

PRIMARY PREVENTION NEEDS FOR PEOPLE LIVING WITH HIV IN HAWAII

By
Jayne Bopp
Richard Barton
Timothy Collins

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Executive Summary

Purpose

The purpose of this project was to develop meaningful and useful recommendations related to designing and implementing interventions to assist people living with HIV in reducing their risks for HIV transmission. A secondary goal was to increase awareness of such interventions and mobilize the HIV-positive community and service providers toward implementation of prevention for HIV-infected persons (PHIP) activities.

Method

Participants were recruited from 3 stakeholder groups: AIDS Service Organization (ASO) affiliated people living with HIV who were at high risk for transmitting the virus, non-ASO affiliated people living with HIV, and service providers to the HIV community.

HIV-positive non-ASO affiliated participants were recruited through doctors, therapists, treatment centers, the syringe exchange program, correctional facilities, and snowball sampled through ASO affiliated people living with HIV statewide. All non-ASO affiliated participants were assigned to individual focused interviews. Six participants engaged in interviews. A private contractor conducted interviews to identify attitudes toward HIV prevention and care services among non-ASO-affiliated people living with HIV

The HIV-positive ASO affiliated participants were required to report having had unprotected anal or vaginal sex with a partner of negative or unknown status within the last year, or having shared needles with a partner of negative or unknown status in the last year. Participants were recruited from ASOs statewide. ASO-affiliated participants were assigned to focus groups when there were enough participants available to do so. The remainder of the participants were assigned to individual focused interviews. Ten people from O`ahu and 4 from East Hawai`i participated in focus groups. One person each from Maui, Kauai, O`ahu and the Big Island participated in individual interviews. Participants were given a short overview on HIV prevention interventions, and then asked to give feedback about how they felt each of these interventions would work for HIV-positive people in their community.

Data from the ASO affiliated and non-ASO affiliated HIV-positive participants was then shared with service providers. Service providers from agencies that could provide more than 1 participant were assigned to focus groups. Others participated in individual interviews. Service providers who were unable to participate in either focus groups or interviews were allowed to inform the process through written feedback. Forty-three service providers from across the state participated in 7 focus groups, 5 individual interviews, and 2 provided written responses.

Project participants were then invited to a meeting where findings from the interviews and focus groups were shared. None of the 6 non-ASO affiliated participants attended. All but one of the ASO-affiliated participants and all but one of the participating service provider agencies attended the meeting. The group was lead through a consensus building process to arrive at draft recommendations for PHIP interventions based on the findings to date.

Findings (Listed in order of prevalence of response by the participants living with HIV; service provider input is in italics.)

- There was a strongly expressed need to ensure confidentiality/anonymity for interventions to be successful. This issue was clearly emotionally charged for all participants, was expressed repeatedly, and participants were unambiguous in their expression of this issue.
- There was an expressed interest in having support around primary prevention issues. *Service providers expressed interest in and openness to providing PHIP services, but also addressed barriers to providing services such as adequate funding, training, staffing, consistency, need for substance use and mental health counseling/treatment, etc.*
- There was an expressed need for services to be provided by other HIV-positive people in order to be effective. Participants clearly felt strongly about this issue, it was expressed repeatedly, and participants were unambiguous in their expression of this issue. *Some service providers agreed that this is a need and others did not*
- There was an expressed need for services to be non-judgmental in order to be effective. Participants clearly felt strongly about this issue, it was expressed repeatedly, and participants were unambiguous in their expression of this issue.
- Trusting the PHIP worker was reported as being extremely important to the participants. The issue of trust overlaps with the participants' need for PHIP workers to be peers, non-judgmental and completely confidential.
- There was an expressed need for stigma-free opportunities for people living with HIV to meet people like themselves, who are also living with HIV, for friendship, sex, dating and relationships. Participants clearly felt strongly about this issue, it was expressed repeatedly, and participants were unambiguous in their expression of this issue.
- There was an expressed need to address issues of alcohol/drug use. This issue was expressed repeatedly, and participants were universally in agreement about this issue. *Service providers also expressed this need and strongly felt that these issues should be addressed.*
- There was an expressed need for a more visible prevention campaign in the public sex environments (PSE) and sex clubs. This issue was expressed repeatedly, and participants were universally in agreement about this issue.
- Participants felt that individual level interventions (ILI) would be most effective. Neighbor Island participants felt that group level interventions (GLI) would not be realistic. They perceived social groups (not GLIs) as possibly useful for recruiting participants into ILIs. O`ahu participants expressed more interest in GLIs, but acknowledged the difficulty of getting people to participate in groups. Likewise, O`ahu participants expressed interest in community level interventions (CLI), but acknowledged that there would be barriers to getting participation. *Most agencies reported difficulty with getting participation in and maintaining HIV prevention GLIs. However most reported good success with social type groups, and some success on O`ahu with particular GLIs.*
- There was an expressed need for PHIP services to be provided by people who share the same gender and/or sexual orientation of clients in order to be most effective. This need was expressed repeatedly and there was clear agreement about it. Some participants felt very strongly about it, while others were less emphatic. *Some service providers agreed that this is a need and others did not.*
- Disclosure was a highly charged issue for participants and reported as a significant barrier to practicing safer sex. The disclosure issues discussed were complex, varied and at times even paradoxical.

- For newly diagnosed individuals or people with confidentiality concerns (like the non-ASO affiliated people and Neighbor Islanders) participants felt that mobile or outreach services, use of the Internet, and/or a warm/hotline would be effective ways to reach them.
- There was an expressed need to address the issue of depression/mental health. *Service providers strongly agreed with the need to address this issue.*
- There was an expressed need for more information on what is safe and what is not safe when it comes to sex.
- The need for PHIP services to be provided by people who share the same race/culture of the client in order to be most effective was discussed. The discussion was limited by the lack of cultural diversity within the participants. It was generally agreed that for some people and some cultures this would be a significant need. *Some service providers agreed that this is a need and others did not.*
- Where discussed there was strong negative reaction to partner counseling and referral services (PCRS) and a clear opinion that PCRS, as we know it is an unacceptable intervention to this group of people. This issue was clearly emotionally charged for the participants and participants were unambiguous in their expression of this issue. *There were mixed feeling about PCRS among service providers. Some felt that it was a user friendly and appropriate service. Some felt that there is a lot of misinformation and negative perception of how PCRS happens. Others felt that there is a big disconnect between the SAPB's view of how partner notification/referral should be done and the input that they are getting from the community.*
- Where discussed, most participants did not feel comfortable talking with their case manager about PHIP issues. *The majority of case managers reported being comfortable addressing safer sex/safer needle-use issues with their clients however they expressed a need for more training in this area. Some clearly expressed discomfort in this area.*
- The 2 most prevalent reasons for not affiliating with ASOs were non-identification with the "HIV subculture" and limited need to approach an ASO.
- All recent seroconverters reported that the person from whom they contracted HIV was aware of being HIV-positive at the time of transmission. Only one of these participants had been informed of that status by their partner before engaging in risk behavior.
- *Several agencies reported that the continuance of an effective statewide syringe exchange program is critical in maintaining prevention of injecting drug use (IDU) related HIV transmission. They agreed that providing and increasing adequate access to sterile syringes for all drug injectors is of utmost importance. One agency suggested that needles should be made available through ASOs.*
- *Most people engaged in care services (and some engaged in prevention) still perceive prevention as simply "handing out condoms and giving the right message." The vast majority of both prevention and care service providers wanted more training on building rapport, how to talk about sexual issues, active listening skills, client centered approaches, doing needs assessments, and behavior change theories and practice.*
- *Most agencies felt that outreach counseling and testing needs to be increased and that targeted counseling and testing interventions with higher risk sub-populations would be beneficial. Neighbor Islanders reported a need for test results to get back in a more timely fashion.*

- *Three ASO care departments and 2 ASO prevention departments saw PHIP as the latest thing that the department of health (DOH) wants to push onto case managers and prevention workers' already overwhelming workloads.*
- *Several service providers and the authors of this study recognized the limitations of the data gathered for this project and acknowledged that we need to find ways to reach the populations that have been under-represented in this process (people of color, women, heterosexual men, injecting drug users, transgendered, sex workers, etc.).*

Conclusions

- There is a pool of people living with HIV in Hawai'i who are engaging in sexual risk behaviors, who want help in reducing those risks, who want more information on sexual risk assessment, and who are open to participating in PHIP interventions.
- The data from the literature review and findings from this project suggest that most new infections in our state come from individuals who already know their positive sero-status, but this evidence is not conclusive. More data is needed. Efforts should be made to target and focus HIV counseling/testing even more than is already being done. Efforts should be focused on identifying subpopulations of high risk populations who show low rates of testing, high rates of risk behavior, and likely or proven presence of HIV within that immediate subpopulation
- Two issues emerged as being most important to HIV-positive participants: The need to ensure confidentiality/anonymity in PHIP interventions and the strong desire to have HIV-positive people delivering the interventions. In general, it seems unlikely that PHIP activities will be successful without ensuring confidentiality or anonymity of participants and without being delivered by HIV-positive people. Should programs be implemented by HIV-negative service providers, it seems likely that a significant number of people will choose not to participate because of a perception that the person delivering the service "doesn't understand where we are coming from." There are significant barriers among some service providers to using HIV-positive staff that need to be addressed. Similarly, it seems that the more the service provider shares commonalities of gender and sexual orientation, the more likely the program will be to succeed. And among some racial/cultural groups, there would appear to be a need for the service provider to share cultural connections, though more data is needed than this project could provide. . (Issues around peer status were very complex and it is strongly suggested that one read the full report section on peer status)
- A major concern for the HIV-positive participants was that services be delivered in a non-judgmental way. Participants responded most favorably to approaches that acknowledged risk behaviors as a fact of life, recognize the difficulty in maintaining safer behaviors, do not put the blame for risk behaviors solely on the HIV-positive person, acknowledge drug and alcohol use, and reframe sexuality as a positive experience. Similarly, disclosure is a highly sensitive and complicated issue for people living with HIV and service providers must understand the full implications of what it means to someone living with HIV to disclose that status. Most service providers go to great lengths to be non-judgmental, but from what we heard, may not always be aware of when they are being perceived as judgemental in this sensitive area.
- PCRS, in the form of someone from the health department contacting sexual partners disclosed by people living with HIV, is found unacceptable by this group of people. They did

appear to be open to innovative approaches where friends can introduce friends to testing without having to disclose having put someone at risk.

- There is strong concern by both service providers and the community participants of this project about the sustainability of PHIP programs and DOH's commitment to them. Significant resources in terms of funding, staffing, support, supervision, and training would be needed to implement sustainable effective PHIP interventions.
- Unfortunately the majority of people engaged in care services (and some engaged in prevention) still perceive prevention as simply "handing out condoms and giving the right message." On-going training on effective HIV prevention interventions must occur on a consistent basis. Luckily the vast majority of both prevention and care service providers wanted more training in areas such as rapport building rapport, how to talk about sexual issues, active listening skills, client centered approaches, doing needs assessments, and behavior change theories and practice.
- ILIs seem to be the most likely type of intervention to succeed, particularly on Neighbor Islands. On O`ahu, there was more openness to GLIs and CLIs, though it may be difficult to get very high levels of participation. A need and desire for social groups was apparent on all islands, and these may prove useful in accessing this population and recruiting for interventions.
- Neighbor Island agencies report doing a good job integrating prevention and care, while there is a big disconnect between the 2 departments on O`ahu.
- We need to find ways to reach the populations that have been under-represented in this process. Only one of the HIV-positive participants in this process was a current sex industry worker, none were active IDUs, none were heterosexual men, there were no women or people of color from the Neighbor Islands and only 5 women and 1 transgendered (TG) person. Obviously there were access barriers for these populations to participate in this study. Further research into the needs of these populations and strategies to include them should be done.
- It appears that there is a perceived subculture around HIV services. For many it offers a sense of community. For others, not wanting to be a part of this "subculture" (often because it is "too gay" or "full of homeless, dirty people" and "drug addicts") becomes a barrier to accessing services. This perceived subculture was a barrier for the majority of the non-ASO affiliated participants and reported as a barrier for local Neighbor Islanders by the high risk HIV-positive neighbor islander participants. Creative ways of addressing this issue need to be found if we are to be as inclusive of all those living with HIV as possible.
- Substance use and mental health issues play a significant role in unprotected sex in Hawai'i. Current treatment options do not adequately address this need.
- Needle exchange is benefiting people with HIV in reducing needle share risk.

Recommendations (For details, please see full report)

1. PHIP interventions should be implemented in Hawai'i
2. PHIP interventions should be performed by trained HIV-positive service providers and/or trained HIV-positive community members.
3. Confidentiality must be ensured and anonymous options should be available.
4. Explore and develop radically different models of implementing PCRS.
5. All staff must be non-judgmental.

6. Ensure consistency of PHIP programs.
7. Provide ongoing training on effective HIV prevention intervention implementation.
8. Sexual risk education must be an ongoing part of PHIP.
9. Provide social support as part of PHIP.
10. Ensure that the substance use issues of HIV-positive people are appropriately met.
11. Ensure that the mental health needs of HIV-positive people are appropriately met.
12. PHIP efforts should utilize ILI for best results. Currently successful GLI should be continued as well.
13. Ensure that on going support around disclosure is available to sexually active people living with HIV.
14. Explore and implement ways to make services more accessible.
15. Current HIV counseling and testing services should be targeted to most effectively identify new positives
16. Provide adequate funding and resources for PHIP interventions.

Acronyms

AIDS	Acquired Immuno-Deficiency Syndrome (the later stage of HIV infection)
ACCT	AIDS Community Care Team (non-profit organization responsible for overseeing Ryan White funding in Hawai`i)
API	Asian and Pacific Islander
ASO	AIDS Service Organization
CAPS	Center for AIDS Prevention Studies (a division of the UCSF)
CBO	Community Based Organization
CDC	Centers for Disease Control and Prevention (federal agency responsible for disease prevention and public health)
CHOW	Community Health Outreach Work (non-profit organization responsible for Hawai`i's legal needle/syringe exchange program)
CLI	Community Level Intervention (HIV prevention intervention that aims to change norms around risk behaviors within a targeted subpopulation)
CSE	Commercial Sex Environment (place where people meet to exchange sex for money or drugs such as prostitution strolls, massage parlors, etc.)
DEA	Drug Enforcement Agency
DOH	Hawai`i State Department of Health
GLI	Group Level Intervention (HIV prevention interventions held in a group setting)
Hawai`i CARES	Hawai`i Community AIDS Resources, Education and Support (community consortium responsible for making recommendations to the SAPB on AIDS services provision)
HAART	Highly active anti-retroviral therapy (combination drug therapy for HIV)
HDAP	Hawai`i Drug Assistance Program (provides free HIV medications to qualified applicants)
HERR	Health Education and Risk Reduction
HIV	Human Immunodeficiency Virus (the virus that causes AIDS)
HRSA	Health Resources and Services Administration (the federal agency that administers the Ryan White CARE act)
HSPAMM	Hawai`i Sero-Positivity and Medical Management Program (Research program that provides free medical exams for people living with HIV)
IDU	Injecting Drug Users
IKON	Island Kane Ohana Network (community level intervention for young MSM on O`ahu)
ILI	Individual Level Intervention (HIV prevention intervention that utilizes one-on-one interactions)
MSM	Men who have Sex with Men (men who are behaviorally gay or bisexual, whether or not they self-identify as gay or bisexual)
NASTAD	National Alliance of State and Territorial AIDS Directors (a non-profit association of national health department directors)
PCM	Prevention Case Management (case management services aimed at reducing HIV risk behaviors)

PCRS	Partner Counseling and Referral Service (originally contract tracing, seeks to identify sex or needle sharing partners of HIV-positive people to introduce HIV counseling/testing and other prevention interventions)
PHIP	Prevention for HIV Infected Persons (interventions aimed at reducing the transmission of HIV by those already infected with HIV)
PLUS	Positive Living for Us Seminar (early intervention seminar for those newly diagnosed with HIV)
PSE	Public Sex Environment (public places where people meet for sex such as parks, bathrooms, beaches and sex clubs, etc.)
PWA/PWHA	Person (People) With AIDS or Person With HIV/AIDS
RFP	Request For Proposal (document to apply for a contract with DOH)
SAFE	Sero-status Approach to Fighting the Epidemic (CDC's first PHIP related initiative)
SAPB	Hawai'i State STD/AIDS Prevention Branch (branch of the state government responsible for the prevention of HIV and care of people living with HIV)
SIW	Sex Industry Worker (people who trade or barter sex for money, goods or services)
STD	Sexually Transmitted Diseases
TB	Tuberculosis
UCSF	University Of California, San Francisco
US	United States (of America)

Introduction

Every new HIV-infection involves an HIV-positive person. Yet until recently very few prevention interventions have been directed to HIV-positive men, women and transgendered. In the past, prevention efforts were not directed toward HIV-positive persons for fear of "pointing the finger" or blaming them for the epidemic. Although AIDS has become less stigmatized in the US, in some communities there is still serious stigma experienced by people living with HIV. AIDS activists have also feared laws criminalizing sexual risk behaviors and further prosecution of injecting drug users (IDU). For the most part prevention efforts for HIV-positive persons have focused on protecting one's own health from the possibility of reinfection with untreatable strains of HIV (even though this is unlikely and has never been proven to occur). Most HIV-positive persons are concerned about not infecting others and make regular efforts to prevent transmission, yet there has been little support for them to gain the necessary skills and tools to adopt new, safer behaviors or maintain current ones.

The Centers for Disease Control and Prevention (CDC) estimate that there are 800,000-900,000 people living with HIV in the US. The number of people living with HIV is growing by about 25,000 people a year (40,000 new cases and 16,000 deaths annually). In the past few years, advances in the treatment and care of HIV-positive persons have helped them enjoy increased health and longer life. For many, this increased health allows for a renewed interest in sexual and drug-using activity. More sexually active and drug-using HIV-positive persons mean the possibility of more new infections. In light of these trends the STD/AIDS Prevention Branch (SAPB), Hawai'i State Department of Health (DOH) designated funds to begin to address these issues. In April 2001 Life Foundation began a 9 month purchase order agreement with the SAPB to facilitate a process to gather information statewide around implementing primary prevention services for HIV-infected persons (PHIP) in Hawai'i.

The PHIP Project's goal was to develop meaningful and useful recommendations related to designing and implementing interventions to assist people living with HIV in reducing their risks for HIV transmission. A secondary goal was to begin to increase awareness and mobilize the HIV-positive community and service providers toward implementation of prevention for positive initiatives. The project consisted of 6 phases: (1) a literature and program review to gather information on successful existing PHIP programs, locally and nationally; (2) to get input from HIV-infected individuals who are not clients of an AIDS service organization (ASO); (3) to receive input from local people living with HIV who are high risk for transmitting the virus; (4) gather information from local service providers about their PHIP needs and issues; (5) to bring together those involved in the PHIP Project's process for a day of sharing, community building and development of final recommendations and; (6) to submit a final report with recommendations to the SAPB. A PHIP Oversight Committee was developed to serve as an advisory/oversight committee for this process. The committee was made up of representatives from prevention and care on O'ahu and the Neighbor Islands and the SAPB. The group met 3 times over the 9-month period to review information, discuss and make recommendations to the PHIP Project coordinators as well as provide input into the final report.

Literature Review

As noted earlier prevention programs have traditionally focused on keeping HIV-negative people from acquiring the virus. Until recently very few programs focused on keeping people living with HIV from transmitting it. In the late 1990's the CDC's first PHIP related initiative was known as SAFE (Serostatus Approach to Fighting the Epidemic) which intended to more directly target the prevention needs of HIV infected individuals and their partners and inform the development of research in this area.

Key Components of PHIP

The following in italics are the key components of a PHIP program taken from the 4 goals of PHIP programs outlined by the CDC in the May 1999 NASTAD HIV Prevention Update:

1. *Increase the knowledge of serostatus among those at high risk for HIV.*
An estimated 30% of people living with HIV do not know their status. Examples of how to do this include: offering counseling and testing in non-traditional settings; expanding or modifying partner counseling and referral services (PCRS) to clinic and ASO or community based organization (CBO) sites and include the use of social networks to bring in new positives; implement/expand voluntary anonymous screening in prisons and implement lower threshold testing.
2. *Offer primary prevention services for HIV infected people, with a priority on those most likely to transmit the virus.*
This must be viewed as a dynamic and on-going process. Linkages must be made to both primary and secondary prevention services. These linkages include: medical, dental, social support, mental health treatment and management, substance use treatment and management, complimentary care, housing, prevention case management, etc.
3. *Assist HIV infected people in accessing care and services, and in going on appropriate treatment regimens.*
This must be viewed as a dynamic and on-going process. An estimated 20% of people nationally who do know they have HIV are not in care, have dropped out of care or receive marginal services. Strategies must be found for assisting clients to remain engaged with service providers. These can include harm reduction strategies and peer-based models.
4. *Assist HIV infected people in treatment adherence.*
This must be viewed as a dynamic and on-going process. Peer based models and treatment advocacy programs can help.
5. *Help HIV infected people maintain risk-reduction behaviors.*
This must be viewed as a dynamic and on-going process – with a life long perspective in mind. In respect to programs, one size does not fit all and one dose is not enough.

Demonstration Projects

In 1998, the CDC funded five health departments to create demonstration projects providing primary HIV prevention for HIV-positive individuals. The states of California, Maryland and Wisconsin, and the cities of Los Angeles and San Francisco, began a variety of programs that address a wide audience including: HIV-positive women, men of color who have sex with men, IDUs, youth, female sex and needle sharing partners of IDUs, and incarcerated men and women. Interventions include: HIV, STD and TB counseling, testing and treatment; referral and linkage to care; prevention case management; HIV-positive peer "buddies"; outreach via social networks; mass media and internet marketing; partner counseling and referral services; skills-building; and community-level forums and social events. More and more studies on effective PHIP interventions are being published. The CDC website (at www.cdc.gov) has a site on "Replicating Effective Programs Plus" that has HIV prevention programs shown to work in the real world. (For a brief outline of some of the PHIP interventions currently being tried or planned see Demonstration Projects – Appendix A.)

What's Been Learned So Far

Past, present and current research has taught us that interventions must be based on specific consultation or formative research with the population to be served. Trying a "one size fits all" approach does not work. The populations we are trying to reach will not come to or stay with a program if it does not meet *their* perceived needs. Multiple types and levels of prevention interventions over time need to be implemented. These interventions must be planned in the context of the population's needs and be both HIV specific and life/health enhancing in general. Harm reduction approaches can be useful because programs must build in flexibility for the intervention itself and for the specific goals of each individual client. So far, some of the correlates of high risk behaviors in HIV-positive persons found include:

- Being under treatment with protease inhibitors
- Reduced concerns about unsafe sex with HAART
- Use of alcohol/drugs before/during sexual encounters
- Less perceived control over condom use
- Lower perceived responsibility to protect partner
- Depression/anxiety (especially in women, gay men)
- Anger/hostility (especially in heterosexual/bisexual men)
- Having an HIV-positive sex or needle sharing partner
- Experience with or fear of domestic/other violence (especially women, some gay men)
- Poverty and its direct consequences (like survival sex, homelessness, etc.)
- Blaming others for one's HIV infection
- Lack of skill in communication about safer sex/safer needle sharing
- Not knowing STDs can accelerate HIV and/or increase transmission
- Avoidance or wishful-thinking coping with HIV in general
- Use of alcohol/drugs to cope with HIV in general
- Assumption that partner is HIV-positive
- Frequenting of PSEs/CSEs

Some correlates of safer behaviors in HIV-positive people include:

- Knowledge of one's HIV status
- Behavioral intentions to use condoms/clean needles, disclose etc.
- Self-commitment to safer sex/safer needle sharing
- Active behavioral coping style with HIV
- Informed partners (about one's status, HIV overall)
- Increasing age
- Responsibility or a commitment to others
- Social support
- Peer norms favoring protection of partners/self

Much remains to be learned. Questions that still need to be answered include: what knowledge from other successful interventions are transferable to people living with HIV and what should be the adaptations; how are women's needs different from men; what are the best venues for interventions; how do you target the highest risk potential transmitters; and how much behavior change is enough?

Current PHIP activities in Hawai'i

Primary prevention interventions for people with HIV range the spectrum from identifying new positives, to treatment and care, to individual, group and community level HIV prevention interventions. The following are current PHIP activities (outside of this project) in Hawai'i.

1. HIV Counseling/Testing - outreach and clinic based
2. PCRS
3. HSPAMM/HDAP Programs
4. Case Management Programs
5. Treatment Advocacy Programs
6. Gregory House Programs
7. Wellness Program at the Waikiki Health Center
8. Syringe Exchange
9. Client Services/Prevention Collaborations
10. Openly HIV-positive staff at various agencies who provide counseling/support
11. Prevention staff who work with HIV-positive clients
12. Substance Use PHIP Pilot Program
13. Group Level Interventions like PLUS, Positively Sexy, and Sexy and Alive
14. Social Marketing like prevention ads in targeted magazines and newsletters
15. Technical Assistance – provided by the CDC in July 2001

Methods

Individual focused interviews and focus groups were the methods of data collection for this project. Results of focused interviews and focus groups were interpreted according to the professional experience of the investigators, the perspectives of key informants, and available scientific data. The nature of the study precluded a quantitative approach.

Focused interview methodology was developed by the U.S. War Department from 1942-45 to test individual and group responses to wartime propaganda. The approach was designed to elicit a range, depth, and specificity of responses. It was also designed provide an understanding of the real life social context in which information is processed, attitudes develop, and practices occur. Since its inception, the focused interview –specifically the focused group interview, in which 6 to 12 respondents interact – has become one of the most widely used methods of sociological inquiry in North America and Western Europe.

This study follows a tradition of psychosocial and behavioral research in which the most salient data is often qualitative, involving a handful of respondents. The complex perceptual and cognitive dimensions of behaviors relevant to HIV primary prevention are uniquely suited to small-scale but highly focused qualitative inquiry. Participants in a focus group are selected because they have certain characteristics in common that relate to the topic of the group. The rule is commonality, not diversity. Statistical representation in the case of the present study is neither relevant nor was it an objective. It should be noted that results of qualitative case inquiry are projectable to the propositions of the study, not to populations. The data collected provides insight into the attitudes, perceptions and views of the participants. The range, depth, and specificity of responses were the primary objectives.

Focus groups and focused interviews can provide useful *guidelines* for program promotion and message design. While focus groups and focused interviews offer many advantages, it is important to recognize their limitations. Focus groups/focused interviews do not provide quantitative data and are not big enough to be of statistical value.

Input from HIV-Infected Persons Not Affiliated with ASOs

For this project we hoped to get input from a variety of individuals living with HIV including those who were not ASO clients. Recruiting for HIV-infected persons not affiliated with ASOs – a population that either avoids or is unaware of ASOs – was a very difficult task. Respondents from this target group were recruited statewide through hundreds of announcements sent to private physicians, therapists and treatment centers, as well as the syringe exchange program and correctional facilities. Respondents were also snowball sampled through ASO clients. To preserve confidentiality of these individuals a private contractor not affiliated with any ASO did all screening and interviews. Only a handful of individuals responded and a total of 6 interviews were completed. Participants received \$75 to participate in a 2-hour interview.

Demographics. Respondents included a Japanese-American heterosexual female, an African-American heterosexual female, 2 gay Caucasian males, a gay African-American male, and a gay male of Chinese-Filipino descent. Respondents varied in HIV risk behaviors and

reasons for not approaching ASOs. All respondents were between the ages of 30 and 50 and resided on O`ahu. An in-depth, comprehensive, stand-alone report was done for this population. Findings and recommendations from this study have been incorporated into this document. The complete study (Privacy, Identity, and Primary Prevention: Focused Interviews with Non-ASO Affiliated Persons Living with HIV in the State of Hawai`i) is available from the SAPB or Life Foundation by request.

Input From ASO Affiliated High Risk People Living with HIV

The next group of HIV-infected people we wanted input from were those at high risk for transmitting the virus. Participants were recruited from each of the 5 main ASOs across the state. Recruitment fliers were sent to every client on ASO mailing lists – about 600 individuals (see Recruitment Flier – Attachment B). Respondents were screened and those reporting unprotected vaginal or anal sex or needle sharing in the past year with someone of HIV-negative or unknown status were selected (see Screening Tool – Attachment C). A total of 18 participants qualified. One focus group with 4 participants was held on East side of the Big Island and one focus with 10 participants was held on O`ahu. One interview each was done on O`ahu, the West side of the Big Island, Maui and Kauai. To facilitate the comfort level of participants all focus groups and all but one interview were implemented by HIV-positive facilitators. Participants were given a short orientation on HIV prevention interventions (i.e. individual, group, and community level intervention, PCRS, outreach, HIV counseling and testing and prevention case management) and then asked to give feedback about how they felt each of these interventions would work for people living with HIV in their community (see PHIP Focus Group Facilitator Guide – Attachment D). Participants were paid \$50 to participate in a 2-hour focus group or interview.

Demographics. Of these 18 participants, 7 were from the Neighbor Islands. Sixteen participants were male, 1 was female and 1 was transgendered (male to female). Thirteen male participants identified as gay and 3 as bisexual. The female and transgendered-female identified as heterosexual. Ages ranged from 32 to 52 years with the average being 42.8 years old. Six identified as Caucasian, 3 as Caucasian/Native American, 2 as African American, and one each as Middle Eastern, Puerto Rican, Mexican/Filipino, Hawaiian/Caucasian, Japanese/Caucasian, African American/Caucasian, and African American/Caucasian/Native American.

Length of HIV-infection among participants ranged from 2 years to 17 years with the average being 12.2 years. Three participants were born and raised in Hawai`i. Length of residency in the islands ranged from 5 to 47 years with the average being 16 years. The average number of times participants reported having unprotected vaginal or anal sex with a person of negative or unknown HIV status in the past year was 5.9 times, the range being between 1 and 30 times.

Additionally, a total of 4 participants reported ever injecting drugs, 1 of whom injected crystal methamphetamine 3 times in the past year. No participants reported sharing injecting drug equipment in the past year. One participant was homeless and severely mentally ill, 2 other persons reported being treated for severe mental health problems, at least 2 participants had an active drug/alcohol use problem, and 1 person reported being in a long-term relationship with an abusive substance-using partner. The majority of participants had a history of drug and alcohol

abuse. At least 1 was a current sex worker. All of the neighbor island participants were gay white males, none of whom were born and raised in the islands.

Input From Service Providers

After gathering information from people living with HIV, a summary of their input was given to key informant service providers statewide (see Service Provider Discussion Guide – Attachment E). These providers were then asked four questions: what are you doing already in primary prevention with positives; given what you’ve heard from people living with HIV do you feel your agency could implement their recommendations now; what barriers would there be; and what additional resources would you need? Service provider participants consisted of staff from both the prevention and client services departments of the 5 major ASOs and staff from the SAPB, ACCT, CHOW Project, and Gregory House Programs. Input from services providers was collected through 7 small focus groups, 5 individual interviews and 2 written responses. Input was collected from a total of 43 service providers. Seventeen providers were from the neighbor islands. Roughly half of the service providers were Caucasian and the gender was about equal as well. At least 6 of these participants were living with HIV.

Day of Sharing

After all the data was collected project participants were invited to participate in a daylong gathering known as the “Day of Sharing”. All of the high risk HIV-positive participants were invited to the day of sharing and all but one attended. Key informants from both prevention and care from each of the service provider agencies were invited and representatives from all but one agency were able to attend.

The goal of the Day of Sharing was two fold. Its first goal was to share the project findings and to come to consensus about what recommendations should be made to the SAPB. This goal was met (see Day of Sharing Summaries – Attachment F). The other goal was more abstract. It was to begin the process of community building around PHIP. This goal appears to have been successful since virtually all the key players who were invited attended and participated. Also, the HIV-positive participants voiced a strong commitment to remain engaged in this process and many participated in “Strategize This” a prevention planning retreat held in February.

Findings

Where Do Hawai'i's New HIV Infections Come From?

Is HIV being transmitted in Hawai'i by those who don't know they are infected, from those who already know their status, or a combination of both? Although we did not look at this question, it is an important one for determining the best way to focus programs and resources (for example, counseling/testing vs. prevention case management).

National data suggests that as many as 30% of people with HIV are unaware of their status (Senterfitt 2001). Local data for some high risk populations suggests that the number of individuals in our state who do not know they are infected may be much lower than 30%. A recent needs assessment for women at risk for HIV in Hawai'i done for the SAPB concluded that there is probably not a large reservoir of HIV infected women who do not know their HIV status (Mueller 2001). A recent evaluation from Hawai'i's statewide needle exchange program shows that due to the success of this program very few IDUs share "dirty" needles/syringes and the number of IDUs testing positive is quite small. Of the 421 HIV tests of IDUs on O`ahu last year, only 2 tested positive (Des Jarlais 2000). These findings suggest that there is probably not a large reservoir of HIV infected IDUs who do not know their HIV status as well. However, there may be small pockets of high risk groups that do not know their status. For example, a Latino MSM and IDU needs assessment done on Maui last year found that only 3 of the 12 high risk participants had ever been tested for HIV, that they had limited knowledge of services and prevention information, and did not use needle exchange (Garcia 2000).

Nationally, somewhere between 19% and 33% of people who know they have HIV engage in unprotected vaginal/anal sex with partners of negative or unknown status (Senterfitt 2001; Kalichman 2001). Of the 18 HIV-positive individuals who participated in focus groups and interviews, 6 people (33%) had been infected fairly recently. All 6 report that the partner who infected them was aware of being positive at the time of infection. Only one of these partners had disclosed his status before transmission. The remaining 12 participants were infected well over a decade ago.

Summary of Primary Prevention Findings from HIV-Infected Persons Not Affiliated with ASOs

The following were the most significant findings as they relate to primary prevention for these 6 participants:

1. Confidentiality vs. anonymity. All respondents prefer anonymous services to confidential services.
2. Gender. Both female respondents reported not having sex since learning of their HIV status. All 4 male respondents reported still having active sex lives.
3. Social desirability. At least 1 respondent gave the impression that he avoided ASOs out of concern that affiliation would reduce his chances of meeting new sex partners should other HIV-positive people disclose his status within the gay community.

4. Unprotected sex. One respondent admitted to having unprotected receptive anal sex with an HIV-negative partner in the past year.
5. Knowledge. All respondents seemed to have a good understanding of how HIV is transmitted. All understood the need for condoms and the risks of unprotected vaginal and anal sex. Male respondents felt that unprotected oral sex is safe.
6. Social support. Male respondents reported needing social support more than female respondents. Female respondents receive social support from family.
7. Complex needs. One respondent has complex psychological counseling needs, directly relating to risk behaviors.
8. Religious-based denial. Religious-based perceptions of being free from HIV due to following moral and spiritual guidelines appears to have influenced 2 of the participants about the decision to receive/adhere to HIV treatment regimens.
9. SIW and IDU. No respondents, nor any persons screened for this sub-set of HIV-infected persons reported being an IDU or SIW.

Summary of Reasons for Non-Affiliation with an ASO

The following reasons were given for non-affiliation with ASOs from these 6 participants:

1. Non-identification with or rejection of “HIV subculture.” Respondent feels that ASOs are characterized by an HIV subculture, with which the respondent is either uncomfortable or does not want to be associated (4 participants).
2. Limited need to approach ASO. Respondent has medical coverage, income, housing, and social support (4 participants).
3. Concern for privacy. Respondent has needs but does not approach ASOs because doing so would let others know of his or her HIV status. This would either result in (a) the respondent being uncomfortable around those who learned of his or her HIV status (2 respondents) or (b) compromise the respondent’s ability to meet other potential social or sexual partners should other HIV-positive people disclose his status within the gay community (1 respondent).
4. Not aware of ASO services. Respondent has financial, psychological, and medical needs but is unaware of services (1 respondent).
5. Embarrassment. Respondent has medical and financial needs but is embarrassed, for religious or social-cultural reasons, of approaching ASOs (1 respondent).

6. Resignation. Respondent has health needs, psychological needs, and financial needs but has resigned to “die naturally” without medical intervention. He is aware of ASOs but wants to distance himself from ASOs and HIV-positive persons (1 respondent).
7. Negative experience with ASOs. The respondent had a negative experience with an ASO (2 respondents).

Summary of Participant Feedback From High Risk People Living with HIV

The following is a summary of the feedback given to us from the high risk HIV-positive participants recruited from ASOs regarding PHIP programming (a total of 4 individual interviews and 2 focus groups were conducted):

1. Participants fervently felt that working with other HIV-positive people like themselves would be most effective (expressed by all interview participants, and through strong/emphatic consensus in both focus groups). The need for HIV-POSITIVE peer-based interventions was repeatedly stressed, including peer based prevention case management. This issue was clearly emotionally charged for the participants and participants were unambiguous in their expression of this issue.
2. Issues of confidentiality were extremely important and Neighbor Islanders could not overstate this issue (all interview participants, both focus groups). O`ahu participants were characterized as being especially concerned about other HIV-positive people breaking their confidentiality. Neighbor Islanders were not only concerned about other HIV-positive clients breaking their confidentiality but participants from 3 separate ASOs reported examples of confidentiality being broken by ASO staff. This issue was clearly emotionally charged for the participants and participants were unambiguous in their expression of this issue.
3. Participants strongly felt that working with those who share peer status in areas other than HIV status would be important, i.e., age/ethnicity/gender/sexual orientation/ substance use history, etc. (all interview participants, both focus groups).
4. All interventions must be non-judgmental (all interview participants, both focus groups). The need for PHIP workers to be completely non-judgmental at all times could not be overstated and was a re-occurring theme throughout all the interviews and focus groups.
5. Trusting the PHIP worker is extremely important (all interview participants, both focus groups). The issue of trust overlaps with the participants need for PHIP workers to be peers, non-judgmental and completely confidential. Participants said that this trust must be established overtime, in a consistent manner (1 interview participant, both focus groups).
6. Participants would like the issues of alcohol/drug use addressed (all interview participants, both focus groups). Participants gave examples of how their own substance use and the substance use of others play a large part in their ability to have safer sex and positive health behaviors.

7. Participants felt a more visible prevention campaign was needed in the PSEs and sex clubs (all interview participants, both focus groups).
8. Participants felt that ILIs would be most effective (all interview participants, both focus groups). Participants felt that GLIs would on Neighbor Islands would not be realistic due to fears around confidentiality and accessibility issues. There was an interest on O`ahu in GLI and CLI, but also a recognition of the barriers to getting people engaged in groups. (all interview participants, both focus groups).
9. Participants were adamant that PCRS as we know it is unacceptable (all interview participants, 1 focus group - PCRS was not covered in the other focus group). Two interview participants told us about a negative experience they had personally had with PCRS. A third participant flat out said they would never, under any circumstances, give a partner's name. Several other participants reported being unable to give names because of anonymous sex (1 interview participant, 1 focus group).
10. Disclosure was a highly charged issue for participants and reported as a significant barrier to practicing safer sex (3 interview participants, both focus groups). The disclosure issues discussed were complex, varied and at time even paradoxical. Participants discussed the fact that often it is their HIV-negative partners who insist on unsafe sex (2 interview participants, 1 focus group).
11. Participants were very open to having support around primary prevention issues and felt that other HIV-positive people would be too (3 interview participants, both focus groups).
12. For newly diagnosed individuals or people with confidentiality concerns (like the non-ASO affiliated people and Neighbor Islanders) participants felt that mobile or outreach services, use of the Internet and a warm/hotline would be effective ways to reach them (3 interview participants, both focus groups). They also felt that PHIP interventions could be effectively done by a private therapist, private physician or through other venues that are general health related (2 interview participants, 1 focus group).
13. Participants would like the issue of depression/mental health addressed (2 interview participants, both focus groups). Participants gave examples of how their own mental health issues play a large part in their ability to have safer sex and positive health behaviors.
14. Participants would like to know what is safe and what is not safe when it comes to sex (2 interview participants, both focus groups). Participants would like to learn about alternatives to unsafe sex (1 focus group). One participant said that this kind of support is needed on a monthly basis.
15. One interview participant felt comfortable discussing PHIP issues with their case manager, most however did not (2 interview participants, 1 focus group – this topic was not discussed with the remainder of participants).

16. Participants, especially Neighbor Islanders (as well as 4 of the non-ASO affiliated participants) suggested that the gay identity associated with most ASOs is stigmatizing and a barrier for many (2 interview participants, 1 focus group). They also reported distance and transportation as barriers to access (3 interview participants, 1 focus group). One focus group reported childcare as a barrier to access.
17. Participants would like to find ways to meet other HIV-positive people for sex, dating, and relationships (1 interview participant, both focus groups). Participants suggested that dating other HIV-positive people alleviates the disclosure issue and provides them with a peer who is “walking in the same shoes” as them.

Summary of Input From Service Providers

The following is a summary of the input given to us by 43 service providers in response to the input received by people living with HIV (responses for this section are not quantified).

1. Some prevention and care staff perceived the fact that they were not peers in terms of HIV status, as well as in things like gender, sexual orientation, race/ethnicity, etc. as a barrier. Other staff reported that they are able to do PHIP work despite not being HIV-positive or not being peers on other levels.
2. Finding appropriate people to hire was reported as a barrier for some agencies, especially hiring skilled peers (i.e. HIV-positive, Native Hawaiian, etc.). Other agencies reported great success in hiring and using peers for prevention efforts.
3. The majority of case managers and client service directors perceived that departmental staff always provided a client centered, harm reduction approach that builds trust and rapport with clients making it safe to discuss PHIP related issues.
4. The majority of service providers statewide repeatedly stressed the need for effective harm-reduction based substance use counseling and treatment.
5. The majority of service providers statewide repeatedly stressed the need for mental health treatment for substance users.
6. Most service providers agreed that adequate supplies of condoms/lube and dental dams need to be widely available to at-risk populations.
7. Especially on O`ahu it was noted that there are perceptions and resistance among some gay community gatekeepers that hamper prevention efforts (e.g. resistance to outreach efforts in some bars and bath houses).
8. Most agencies reported difficulty with getting participation in and maintaining HIV prevention GLIs. However most reported good success with social type groups, and there has been some success on O`ahu with GLIs.

9. There were mixed feeling about PCRS among service providers. Some felt that it was a user friendly and appropriate service. Some felt that there is a lot of misinformation and negative perception of how PCRS happens. Others felt that there is a big disconnect between the SAPB's view of how partner notification/referral should be done and the input that they are getting from the community about how it is actually being done.
10. The majority of case managers reported being comfortable addressing safer sex/safer needle-use issues with their clients however they expressed a need for more training in this area. Overall, service providers were positive about doing primary prevention work however they felt that the prevention departments should be the ones to take the lead on PHIP.
11. All the Neighbor Island ASOs reported a close collaboration between prevention and client services departments – the O`ahu ASO reported much less of a collaboration between these departments.
12. Most agencies felt that outreach counseling and testing needs to be increased and that targeted interventions with higher risk sub-populations would be beneficial. Neighbor Islanders reported a need for test results to get back in a more timely fashion.
13. Most care providers agreed that health care professionals (i.e. doctors and nurses) should be trained in prevention interventions.
14. Native Hawaiian workers addressed issues of stigma and shame that have to be dealt with before one can even get to the point of discussing unsafe sex/needle sharing. Native Hawaiian workers agreed with client input that peers should be used and ILIs would be best with this population. But even using peers and doing ILIs Native Hawaiian workers cautioned that it would still be very challenging and require great investment in time and energy to build trust. Native Hawaiian workers reported that they are already overtaxed as they are expected to be all things to all Native Hawaiian peoples when it comes to HIV/AIDS.
15. Several agencies reported that the continuance of an effective statewide syringe exchange program is critical in maintaining prevention of IDU related HIV transmission. They agreed that providing and increasing adequate access to sterile syringes for all drug injectors is of utmost importance. One agency suggested that needles should be made available through the ASOs.
16. Three ASO care departments and 2 ASO prevention departments saw PHIP as the latest thing that the DOH wants to push onto case managers and prevention workers already overwhelming workloads.
17. Most people engaged in care services (and some engaged in prevention) still perceive prevention as simply "handing out condoms and giving the right message." The vast majority of both prevention and care service providers wanted more training on building

rapport, how to talk about sexual issues, active listening skills, client centered approaches, doing needs assessments, and behavior change theories and practice.

18. The majority of services providers reported concern over the fact that their agencies are already stretched thin from level funding from the state and decreased funding from other sources, with increased workloads. They pointed out that to do these programs well would require more staffing, more training and more supervision.
19. Additional staffing issues identified by service providers included: a need to have staff to train and mentor new employees; the need for mental health counseling for staff to deal with counseling/debriefing/support around their work (i.e. clinical supervision); the need for more supervision; and most service providers reported the need for more funding for staffing.
20. Some service providers strongly felt that DOH needs to define clearly to the agencies that it subcontracts with exactly what PHIP is and how to do it, and that PHIP guidance from HRSA/CDC needs to be shared at all levels of planning and implementation.
21. Several service providers recognized the limitations of the data gathered for this project and acknowledged that we need to find ways to reach the populations that have been under-represented in this process (people of color, women, heterosexual men, injecting drug users, transgendered, sex workers, etc.).

Conclusions

Hawai'i's New HIV Infections

Looking at the data from the literature review and findings from this project we suspect that most new infections in our state come from individuals who already know their positive sero-status and the reservoir of infected individuals who do not know their status is probably quite small. This would suggest that PHIP activities should focus on working with high risk HIV infected individuals and that counseling and testing should be made as focused on and accessible to those most at risk as possible. This however is a hypothesis and more research is needed. The roles that the US military and tourist populations possibly play in our new HIV infections certainly needs to be explored further (STD data suggests they may play a role in our epidemic).

Interventions Performed By Peers

All of the high risk HIV-infected people we talked to were adamant that they wanted someone who is HIV-positive to provide the interventions. This is coupled with the fact that “all available data suggest that peer-based interventions are superior for achieving behavior change” (Corby 1997).

Certainly, most HIV-negative service providers have experience addressing prevention issues with HIV-positive clients (some very successfully). But clearly, the minority of HIV-positive participants we talked to said they would be comfortable talking with HIV-negative service providers about risk behaviors, and several stated discomfort with talking to members of the opposite gender or sexual orientation as well. While HIV status concordance was the most pressing issue when identifying peer status, the next most prevalent concern was around peer status in terms of sexual orientation and gender. Again, while a significant minority of people we talked with felt comfortable discussing risk behaviors with people who were not of the same gender or sexual orientation, the majority expressed discomfort with this and indicated that their friends would also be uncomfortable in the same situation. This came up in terms of comments like that of a gay male participant who said, “I don’t want to talk to some straight woman about what guys do. What does she know about gay men’s sex lives?” or a woman participant who said, “We need someplace where us girls can talk. I don’t wanna be talking about sex and stuff and HIV and what’s going on ‘down there’ with a bunch of guys.”

The issue of race/culture also came up as a barrier to services, but was more one sided. Most Caucasians seem open to getting interventions from local service providers as long as they had a peer bond like HIV status concordance or sexual orientation concordance. But, it seems, from the input we received, that there are a significant number of local folks who would find it difficult to receive services of this nature from Caucasian service providers.

Of course, there are exceptions to this and many people feel comfortable to receive services from someone who is not a peer on these levels. Likewise, many service providers have had prevention interactions with people living with HIV who are not peers with them in these terms. At one Neighbor Island agency, staff reported that the diversity of their staff provided opportunities for clients to address PHIP issues with whomever they felt most comfortable. They report that clients did tend to address these issues with staff they felt a peer relationship with because of gender, age, HIV status, ethnicity, or other factors.

In spite of clear messages from the research and from the high risk HIV-positive participants of this study that staff doing PHIP work must be peers, some service providers (especially those that had few or no peers on staff) sincerely felt that peers were not necessary. One situation we encountered exemplifies this issue particularly well. An HIV-positive client from one agency said, “Who would I talk to here? Look at the staff. There’s nobody positive here!” Ironically when interviewed, the staff of this same agency strongly expressed that they were capable of doing PHIP work and clearly stated that there was absolutely no need for them to be peers.

Taken altogether it is clear to us that PHIP services must be made available from HIV-positive service providers and every attempt should be made to create peer connections on as many levels as possible. If not, we will lose the opportunity to be as effective as possible with a large part of the population we are trying to reach, perhaps even the majority. It is important that SAPB and ASO staff recognize the fact that trained/appropriate HIV-positive peers will be more effective than non-peers. The acknowledgement of appropriate peers being more effective than non-peers can be very threatening and invalidating to non-peers who are “trained professionals” or who have made a career out of this kind of work. These feelings can be barriers to implementing peer based models and must be acknowledged and worked through if program implementation is to be successful.

Confidentiality/Anonymity

Issues of confidentiality were extremely important and Neighbor Islanders and non-ASO affiliated participants could not overstate this issue. For Neighbor Islanders the importance of confidentiality and anonymity was compounded due to the small/interconnected nature of their communities. Many of these participants felt that it was too explicit to state that people are having unsafe sex and expect them to come to an intervention related to that. “No one in a small community wants to admit to their unsafe behavior because of its implications (what they are doing and what other people in their community are doing)”.

O`ahu participants were characterized as being especially concerned about other HIV-positive folks breaking their confidentiality. Neighbor Islanders were not only concerned about other HIV-positive folks breaking their confidentiality but participants from 2 separate ASOs gave accounts of confidentiality being broken by staff. A third Neighbor Island participant reported feeling their confidentiality within the agency had been broken when a prevention worker reported their sexual behavior to a case manager who later “attacked” the participant about this behavior. Whether these accounts of ASO staff breaking client confidentiality are true or not, they represent a serious barrier for access.

Interestingly (and in contrast to the information gathered about peer status), some clients and one ASO worker reported that people said that if the PHIP worker was not a part of the community at all (like from another island or not part of the Hawaiian community) they would feel more confident that their confidentiality/anonymity would be protected. None the less, not only must providers be aware of their own and their agency’s attention to confidentiality, but they must create innovative ways of protecting participants in interventions from being identified by other HIV-positive people and the general community.

Non-judgmental Approach

Along with peer status and confidentiality, being non-judgmental was viewed as critical to being able to trust the person doing PHIP interventions. All staff whether peers or non-peers, whether in prevention or care, must be consistently non-judgmental. Additionally, interventions must help people living with HIV to feel good about themselves as HIV-positive and sexual. One participant noted: “Whoever is doing the PHIP needs to be able to talk about risk behaviors as a fact of life, not be shocked by them happening. Talk about this stuff in terms we use and in terms that see sex as normal and a good thing. Don’t talk about ‘prevention’ and ‘interventions’. It has to be okay that you party. When you’re using you don’t want to hear lectures, but you still might want support”.

Some case managers report being comfortable addressing safer sex/safer needle-use issues with their clients but others did not. The need for support in this area was illustrated during data collection at one agency. At one of the focus group done with client services staff, the supervisor adamantly stated at the beginning of the group that their staff is always non-judgmental and client centered. Not only did this statement shutdown any chance of having an open and honest discussion with the staff around this issue but it was directly refuted by input previously given to us by a client of that same agency who shared about a recent incident where they felt harshly judged by a case manager about their sexual behavior. Clearly support on being non-judgmental for all staff (prevention and care) needs to continue on an on going basis.

PCRS

The current model used by DOH for PCRS while effective with some groups such as women, has been historically less effective for high risk groups like MSM. This is no surprise based on the literature. A 2-year study done in Utah found that women were more likely to cooperate and named more partners and that heterosexual men and MSM were significantly less likely to name partners (Pavia 1993). Information from the DEA website suggests that PCRS has limited success with IDUs. And while PCRS may be effective for some high risk groups who chose clinic based testing, it has been far less successful with clients who chose outreach HIV testing.

Every HIV-positive person we talked to in this study about PCRS had strong negative reactions to it. For example one O`ahu participant was adamant that he would never disclose his sex or needle sharing partners to the health department if a worker was going to be sent to that person’s home or work: “I don’t care if they were going to send their favorite celebrity or the president of the United States. I would never do that to them.” He felt that if notification was going to be done at all, it should be done by phone or mail. Similarly Neighbor Island participants felt that people would “freak” if the “AIDS guy” or “Syphilis guy” showed up. Two Neighbor Island participants reported a negative experience with partner notification. The first had Syphilis and the health department called his job, identified themselves as the health department and told his employer they needed to talk to [participant’s name deleted] right away. Although the health department did not disclose he had syphilis the participant felt completely violated. The other participant was contacted by a mainland health department after moving here. He reported that this “scared the hell out of me”. Several participants feel that a

community clinic setting or private doctor's office could be a good site for PCRS, in that others would not know why they were going into that office.

While some DOH service providers reported that PCRS was effective, others disagreed. Since there is disagreement within DOH about the effectiveness of PCRS and since participants were clearly against the current way PCRS is perceived, the single most effective change might be to ask people to help us promote HIV counseling and testing without having to identify others as sexual or needle sharing partners. In our interviews people told us that a barrier to participating in this research for their friends (especially on Neighbor Islands) was having to admit having unprotected sex and the implications that has, not only for them, but also for their partners in a very small community. Clearly this is a barrier for them to participating in PCRS, as well. Instead of asking, "Would you like help in telling your partners?" maybe we should be saying something like, "We are trying to offer HIV testing to more people in our community. Do you know other people who might be interested in getting an HIV test?" Of course community based counselor/testers might have better luck with this approach than someone affiliated with the DOH. It will be difficult to convince most people that the DOH is not interested in tracking down people engaging in "bad" behavior.

Consistency

Although most service providers recognized the importance of PHIP, it is seen by many as the latest thing that the DOH wants to push onto case managers and prevention workers already overwhelming workloads. Says one case manager, "Last year it was adherence, this year it's PHIP, and next year it will be something else. These programs all come and go and they never give us the additional resources to implement these programs and keep them going in a consistent way." Likewise, prevention workers feel a need to make this a consistent, supported program, "not just the new flavor of the month". Furthermore, the HIV-infected participants of this project reported wanting to see the same workers doing the same intervention, in the same place, consistently over time. They expressed frustration over "programs that come and go."

Clearly there is concern by both service providers and the community participants of this project about the sustainability of PHIP programs and DOH's commitment to them.

HIV Prevention Training for Service Providers

Unfortunately we found that most people engaged in care services (and some engaged in prevention) still perceive prevention as simply "handing out condoms and giving the right message." Prevention workers receive very cursory training in the skills and science of HIV prevention. ASO prevention department culture tends to minimize the importance of the skills and science of HIV prevention, relying more on individual experience. Of course, some agencies/individuals in care services understand prevention interventions better than others and are better than others at referring clients to prevention services.

The vast majority of both prevention and care service providers wanted more training on building rapport, how to talk about sexual issues, active listening skills, client centered approaches, doing needs assessments, and behavior change theories and practice. Some service providers talked about the need for executive directors and others involved in the higher areas of

planning to have a better understanding of PHIP and what is or is not happening within their agencies or agencies that they fund.

Several service providers felt that it was important that DOH clearly defines to the agencies that it subcontracts with exactly what PHIP is and how to do it. PHIP guidance from HRSA/CDC needs to be shared at all levels of planning and implementation. As one worker said: “We need to clearly define what a PHIP program should be. What should it yield? It is the state department of health’s job to clearly define how to implement these programs and to give effective guidance”.

These findings suggest that those most likely to be responsible for implementing PHIP programs need and want training and ongoing support to do so. These providers would need to see the benefit for doing PHIP at all levels of their agency and DOH must be committed if these programs are to be effective.

Barriers/Facilitators to Client Participation in Prevention Interventions

The findings suggest that individual level interventions should be the focus of PHIP, but on O`ahu overlapping interventions may be possible. The majority of participants felt that individual level interventions (ILI) would be most effective. Neighbor Island participants felt that group level interventions (GLI) would not be realistic. They perceived social groups (not GLIs) as possibly useful for recruiting participants into ILIs. O`ahu participants expressed more interest in GLIs, but acknowledged the difficulty of getting people to participate in group interventions. All participants felt social groups would be popular. Likewise, O`ahu participants expressed interest in community level interventions (CLI), but acknowledged that there would be barriers to getting participation. Most agencies reported difficulty with getting participation in and maintaining HIV prevention GLIs. However most reported good success with social type groups, and some success on O`ahu with particular GLIs.

It appears that there is a perceived subculture around HIV services. For many it offers a sense of community. For others, not wanting to be a part of this “subculture” (often because it is “too gay” or “full of homeless, dirty people” and “drug addicts”) becomes a barrier to accessing services. This perceived subculture was a barrier for the majority of the non-ASO affiliated participants and reported as a barrier for local Neighbor Islanders by the high risk HIV-positive neighbor islander participants. Creative ways of addressing this issue need to be found if we are to be as inclusive of all those living with HIV as possible.

Other barriers need to be addressed as well. In many communities, religion plays a key role in how people living with HIV conceptualize their disease. This can become a barrier to seeking HIV services and was found to be a barrier for two of the non-ASO affiliated participants. We can speculate that this is also a barrier for those in small communities like on the Neighbor Islands and rural O`ahu. Gatekeepers within a community can provide us access to individuals but they can also bar access of prevention interventions (e.g. resistance to outreach efforts in some bars and bath houses). Stigma, fears of rejection, all the negative messages people get in their home communities also work against prevention efforts. Also, the issues of transportation and childcare must be addressed.

Finally, we need to find ways to reach the populations that have been under-represented in this process. Only one of the HIV-positive participants in this process was a current sex industry worker, none were active IDUs, none were heterosexual men, there were no people of color from the Neighbor Islands and only three women and one TG. Obviously there were access barriers for these populations to participate in this study. Further research into the needs of these populations and strategies to include them should be done.

Sexual Risk Education

People living with HIV want to know what is and isn't safe sexually. For the most part they know that anal or vaginal sex without a condom and needle sharing is high risk, but outside of that they want more information. Scientific unknowns cloud the issue of self-protection as a motivator for people living with HIV to practice safer sex/needle sharing. These include questions about re-infection and super-infection, pregnancy risk, sustained effectiveness of antiretroviral therapy (more than five years), infectiousness with low viral load, relative infectiousness of women versus men, the significance of specific STDs for transmissibility of HIV, and the potential for infection through oral sex. The interest in this topic appears to be enough that, in and of itself, getting accurate information on sex is an incentive to people living with HIV to participate in PHIP interventions. This topic arose in virtually every one of the interviews and both focus groups. Given the ambiguity around sexual acts, like oral sex or positive-positive sex, addressing these issues can lead into fruitful discussions around risk assessment and opportunities for motivational interviewing. It was noted by one participant that this support needs to be on an on-going, long term basis. The research also backs this idea up. Living with HIV is life long process therefore primary and secondary prevention efforts need to be life long as well.

Social Support

The need most often expressed by the HIV-positive participants of this study was for social opportunities. This seems to translate to stigma-free opportunities to meet people like themselves, who are also living with HIV, for friendship, sex, dating and relationships (one could probably say the same for HIV-negative people, but with HIV there are a whole bunch more issues). This need was expressed throughout our interviews/focus groups. There are a number of distinct reasons for doing this from a PHIP perspective. A few of these reasons are:

- Every time an HIV-positive person has sex with another HIV-positive person, instead of an HIV-negative or unknown status person, an opportunity for seroconversion has been avoided
- When two people know each others' status there is no need for disclosure which is a difficult and often overlooked process that people with HIV are generally happy to avoid
- HIV-positive people in serodiscordant couples often feel pressure from the negative partner to have unprotected sex (Buchacz 2001; participants for this study). By creating opportunities for sero-concordant relationships this dynamic may be avoided
- HIV-positive people in serodiscordant couples have higher rates of unprotected sex outside their primary relationships (Hoff 1999). By creating opportunities for sero-concordant relationships this dynamic may be avoided
- These social opportunities may also provide educational opportunities to develop healthy relationship skills. For women, straight men, and gay men alike, unhealthy relationship dynamics, including domestic violence contribute to HIV transmission in multiple ways (Gomez 1999)).

- People living with HIV tend to isolate. This adds to the dynamics of depression that many people living with HIV experience. Research shows depression is often a major contributing factor to both poor treatment adherence and unsafe sexual practices (Brown, et al., 1992; Chuang, Jason, Pajurka, & Gill, 1992).
 - Social activities can provide opportunities for service providers to develop trust relationships with participants that can be nurtured into more intensive individual level intervention.
- Taking all of this into account, social support and social opportunities for people living with HIV can play an important part in PHIP interventions.

Substance Use

The important role that substance abuse plays in the HIV epidemic has been repeatedly documented by the research and was cited as an issue that must be addressed by the high risk HIV-infected participants and by virtually all service providers. Non-injecting HIV-positive substance users show high levels of continued sexual risk behavior with HIV-negative and unknown-status partners. Substance use is highly correlated with high risk sexual behavior (Gomez 1999; Paul 2001; Purcell 1998). Interestingly, a significant number of the high-risk participants in this project were either former or active substance users. All evidence suggests that Hawai'i's needle exchange program is a very effective PHIP intervention, minimizing HIV transmission within this population. However research from the mainland shows that many HIV-positive IDU continue to engage in high risk sexual behavior. Many HIV-positive IDU report infrequent condom use with primary partners, even though they may use condoms consistently with casual partners (Knight 1999; Reitmeier 1999).

As for treatment options, abstinence based programs are not fully meeting the treatment needs of substance users for several reasons:

- Some people are committed to long-term drug use.
- It can take years of recovery readiness before an individual is ready to try an abstinence program. Few resources are devoted to recovery readiness.
- Treatment slots (beds) are not available on demand
- Insurance companies are consistently reducing the amount of treatment time they will pay for, leaving people with an unstable foundation for continued sobriety
- Most people make several attempts at sobriety before staying abstinent for significantly long periods. Insurance companies are limiting the number of times that one can go through treatment

Taken all together it is clear that substance use plays a significant part in the lives of people living with HIV and in HIV transmission. Substance use issues cannot be ignored and traditional models of dealing with substance abuse must be radically changed if they are to be effective PHIP interventions.

Mental Health

Research shows that mental health issues (specifically depression, childhood sexual abuse survivors and sexual compulsion) contribute greatly to sexual risk behaviors, substance abuse, and negative medical outcomes (Brown, et al., 1992; Chuang, Jason, Pajurka, & Gill, 1992; Kalichman 1997; Paul 2001). A large portion of the HIV-positive participants in this study reported this as an issue that needs to be addressed. Virtually all service providers

discussed the huge need for effective and accessible mental health services as well. Access to treatment for mental health issues for people living with HIV is virtually non-existent and the current DOH mental health program effectively excludes people actively using substances from accessing mental health services by setting up an artificial boundary of whether drug use or mental illness is the “primary diagnosis”. The end result is that many people living with HIV who have mental illnesses and are actively using drugs cannot access mental health services. While Waikiki Health Center’s Title III counseling program is beginning to address this need, clearly much more needs to be done statewide if PHIP programs are to be effective.

Disclosure

There are societal, legal, cultural and interpersonal disincentives to disclosing for people living with HIV. In the words of one participant, “HIV-negative people don’t get the full implications of what disclosure means.” In general, human beings are much more reluctant to talk about sex with their partners than to engage in it. During sexual risk behaviors, there is often little or no verbal communication, particularly in PSEs. Studies have found that MSM participating in sexual risk behaviors report assuming that if their partner does not say that he is negative and is willing to engage in risk behavior, then he must be HIV-positive or not care about infection. (This assumption is in direct contrast to HIV-negative men who assume that if HIV status is not discussed, then their partner must be HIV-negative because “if he was positive and putting me at risk, surely he would tell me”). The HIV-infected participants in this study echoed these findings. They reported feeling that people in PSEs who did not bring up condom use or do want to use condoms were either already infected or not concerned about being infected.

Some participants expressed needing more support for positive/negative couples. As one participant said: “People usually assume that if you’re positive, you’re the one who doesn’t want to use condoms. But we need support in dealing with HIV-negative partners who don’t want to use condoms and need for service providers to not assume we’re the ‘bad guys.’”

Clearly PHIP interventions need to address the “who, what, when, where, why and how” of disclosure. Due to the often highly charged issues around disclosure the need for these interventions to be client centered, non-judgmental and harm reduction based is essential.

HIV Testing

The data collected within the focus groups/interviews of people living with HIV suggests that a significant majority of new infections come from people who know they are HIV-positive. Further research to verify this hypothesis may be advisable. If this hypothesis is true (or if we are willing to assume that it is true, based on what we know now), it would indicate that we should not put additional funding into counseling and testing beyond what we are currently devoting to this effort. If it is not true, then certainly we should add to strategic counseling and testing resources.

Regardless of whether resources are increased or remain level, current counseling and testing programs need to be specifically aimed at identifying those who are positive, but do not know it (as opposed to counseling/testing HIV-negative people engaging in some risk behavior and the “worried well”). To this end, efforts should be made to target and focus HIV

counseling/testing even more than is already being done. Efforts should be focused on identifying subpopulations of high risk populations who show low rates of testing, high rates of risk behavior, and likely or proven presence of HIV within that immediate subpopulation (i.e. MSM/IDU). The more specific our populations are, the more effective our interventions will be. For example the evaluation done for CPG in 1999 found that the peer based outreach pilot test Orasure program at Life Foundation was more likely than DHHC to test gay-bi men, younger gay/bi men, gay/bi men with more partners and less condom use, MSM with more alcohol use, and first time testers. The Orasure outreach program was 7 times more likely to test an MSM HIV-positive than the Diamond Head Health Center. The social network approach (encouraging HIV-positive persons to provide information and outreach to peers who might be positive) is one way to create a more efficient and targeted approach to HIV testing and counseling for those at greatest risk. One example of this is the “Each One, Reach One” program (Senterfitt 2001). This social network approach is also one alternative or complement to traditional PCRS strategies.

Resources

Across the board, subcontracted agencies are experiencing severe financial difficulties. AIDS giving has been down for years now, and things only got worse after September 11th. State and Federal funding has remained relatively flat, while the workload expected in every contract expands. Many service providers are feeling “maxed out” and are having difficulty handling the stressful nature of this work. Some service providers, in both prevention and care see PHIP as the latest thing that the DOH wants to push onto their existing workloads and assume it will be without sufficient additional resources. As one service provider put it, “You can’t just implement a program or add to responsibility of contracts without recognizing the need for additional resources – financial, training, administrative support, supervision.” The bottom line question is “Who’s gonna pay for this? How are people going to get trained? The state should provide resources available from the federal government to support implementation of these programs”.

Agencies are already stretched thin from level funding from the state and decreased funding from other sources, and increased workloads. To do these programs well will require more staffing, more training, more supervision. In light of these findings and based on the experience of the PHIP Project coordinators, it is our opinion that for most prevention programs to be strong and successful a full time prevention department coordinator (or equivalent) is needed. Funding should be adequate enough that this program director does not have to do front line work and can focus completely on program development, implementation (including peer staffing/peer volunteers) and evaluation.

Recommendations

1. PHIP Interventions Should Be Implemented In Hawai'i

- There is a pool of people living with HIV in Hawai'i who are engaging in sexual risk behaviors, who want help in reducing those risks, and who are open to participating in PHIP interventions.
- ILI are most likely to succeed.
- Already existing successful GLI should be continued.
- The feasibility of GLI focusing on specific issues, i.e. serodiscordant couples or relationship skills, should be explored, particularly on O'ahu.

2. PHIP Interventions Should Be Performed By Trained HIV-Positive Service Providers And/Or Trained HIV-Positive Community Members

- Staff PHIP positions, including health educators, counselor/testers, case managers, prevention case managers and PCRS staff with HIV-positive people at DOH and subcontracted agencies.
- Seek out, develop, recruit and train HIV-positive people from within the HIV community to do prevention work and fill staff positions.
- As much as possible, peer status on issues secondary to HIV status, such as gender, sexual orientation and culture (local vs. Haole) should be accommodated. If at all possible gay men should be matched with gay men, women with women, local with local, etc. unless clients request otherwise.
- There should be at least one gay man, one Native Hawaiian (or other appropriate local person), and one woman living with HIV available to all programs to develop peer relationships. This may mean one person statewide who travels and can be a resource to agencies or one person within the agency. (Obviously, gender and sexual orientation are not mutually exclusive to culture – the worker could be both local and gay or local and a woman). Male heterosexual and IDU representation should be strongly considered as well.
- Recognize that the idea of hiring peers can be threatening to existing non-peer staff because it can make them feel invalidated. Creative ways of dealing with existing DOH and ASO staff that do not buy into peer models must be found.
- On advertisements for positions, include the phrase, “HIV-positive encouraged to apply.”
- If a suitable full-time HIV-positive person to develop or hire absolutely cannot be found, an HIV-negative staff person can use stipends to recruit and train part-time HIV-positive volunteer peer educators/buddies.
- Provide technical assistance around staffing to DOH and subcontracted agencies that perceive hiring HIV-positive workers as an insurmountable barrier or unnecessary.

3. Confidentiality Must Be Ensured and Anonymous Options Should Be Available.

- Use outreach to meet people at times and places of their choosing.
- Recruit health care workers (doctors, nurses, etc.) to offer PHIP interventions or perhaps there may be innovative ways of applying this principle to PHIP workers in general.
- Provide interventions over the telephone and/or the Internet.
- Have the intervention provider available at places where people might be likely to meet someone and strike up a conversation.

- Whenever possible include anonymous service delivery options.
- Use social marketing tools like having a campaign within the HIV-positive community around respecting each other's confidentiality.

4. Explore and Develop Radically Different Models Of Implementing PCRS.

- Link HIV-positive people to existing HIV counseling/testing programs, and support them in referring their friends (who may or may not be sex and/or needle share partners) to these services (i.e. Each One Reach One model).
- Offer incentives to HIV-positive people who bring friends to get tested.
- Offer incentives to high risk groups who come in to be tested.
- Utilize peers to encourage referrals.
- Hire HIV-positive people to do PCRS.
- Notification should be done by mail rather than in person or by phone.

5. All Staff Must Be Non-Judgmental.

- All professionals and volunteers (care and prevention) working with HIV-positive clients should be trained in harm reduction approaches which recognize the existence of risk behaviors as a fact of life and encourage a non-judgmental approach to addressing that reality.
- Anyone delivering PHIP interventions (care and prevention) should avoid any tendency to blame or shame the person engaging in risk behaviors. Doing this only promotes more shame and disengages the person from seeking further help. Particularly, do not make the frequently erroneous assumption that the HIV-positive person is the one insisting on unsafe behaviors - particularly in sero-discordant relationships, the negative partner is often the one encouraging more risk.

6. Ensure Consistencies Of Prevention Programs.

- If DOH or CBOs are not planning to commit resources enough to do this adequately and keep up the momentum for at least several years, they should not begin it at all.
- Focus efforts – it's better to focus on 1 or 2 populations and/or geographic areas and do them thoroughly than to spread a program so thin that it doesn't really meet anyone's needs.
- For outreach programs focusing on a particular place (PSE, bar, prostitution strolls, etc.), it is important to establish and maintain a consistent presence in the targeted location over a long period of time.
- If a program is being run out of an office, make sure program staff is consistently available.
- Use technology like pagers, on-line chatting, voicemail, and cell phones to make program providers more accessible.

7. Provide Ongoing Training On Effective HIV Prevention Intervention Implementation.

- All workers (care and prevention) serving people with HIV should have basic training in prevention science and know how to engage someone living with HIV in effective behavior change conversations around risk reduction when opportunities arise (beyond "handing out condoms and giving the right message"). Case managers should not be expected to do PHIP as a criterion of their job performance (i.e., be evaluated on doing X number of risk reduction

consultations per year), but should be comfortable providing some level of PHIP counseling if the client is willing to go there with them.

- A list of core competencies for prevention workers should be developed delineating skills and knowledge necessary to implement prevention models (i.e. skill in identifying the stage of change a client is in and applying an appropriate intervention for that stage). Ways of measuring levels of competency in these skills, and levels of knowledge, should be developed and implemented. The DOH and CBO supervisors should make continuous intensive efforts to bring all workers up to a level of mastery in these competencies. Particularly, expertise in motivational interviewing skills should be developed.
- Referrals from care services (i.e., case management, housing personnel, etc.) to prevention interventions/prevention workers should be strengthened. At least on O`ahu, multiple levels of intervention should be available and referrals should be made between interventions (i.e. referrals from IKON to Positively Sexy, or from PLUS to the TG program, etc.)

8. Sexual Risk Education Must Be An Ongoing Part of PHIP.

- Addressing actual risks of sexual acts (even though we don't have concrete answers to some questions) should be used to engage people in PHIP activities.
- People living with HIV should be given the most current, accurate information in terms they can understand and assisted to translate this information into defining what they are and are not willing to do sexually within the context of HERR.
- Interventions should be developed that do not require an admission of risk to participate. For instance, the focus of the intervention would not be "peer counseling for HIV-positive people who have unprotected sex" Rather it may be "peer counseling around sex, dating and relationships," leaving the door open for people to participate without having to implicitly or explicitly admit risk behavior. The model may make an assumption that risk behavior happens and keep that as a hypothetical, unless or until participants begin to talk about their own experiences.

9. Provide Social Support As Part Of PHIP.

- Provide social opportunities for people living with HIV/AIDS, as appropriate to the subpopulation being targeted.
- Incorporate educational aspects into social opportunities (carefully – test the waters of what participants will stand before they feel like they've been roped into a "workshop").
- Use these social gatherings to develop trust relationships with participants to further other PHIP intervention.
- Offer experiential learning opportunities (classes, workshops, support groups, etc.) on healthy relationship and communication skills.

10. Ensure That The Substance Use Issues Of HIV-Positive People Are Appropriately Met.

- Continued support and possible expansion of the needle exchange program is the most effective PHIP intervention we can provide for injecting drug users.
- More effort needs to be placed on researching how we may most effectively engage HIV-positive IDU in PHIP interventions and what interventions, beyond needle exchange, might be most effective. It is reasonable to expect that this effort may be slow in producing results, as time will probably be needed to develop trust relationships.

- The role of peer educators in both IDU and non-IDU substance users for PHIP should be explored.
- Harm reduction based counseling models for HIV-positive substance users must be developed and implemented. These may be individual or group level interventions and need to address risk behaviors for HIV transmission and treatment adherence issues.
- Substance use treatment beds should be available on demand for HIV-positive people. Resources need to be available to cover costs of these services. HIV-positive people should be given the support to attempt abstinence as many times as it takes, if they want to do so.
- Provide housing opportunities for injecting and non-injecting drug using HIV-positive people and allow them to maintain that housing despite drug related challenges.
- Support current and future legal efforts to make sterile syringes available to IDUs
- Decriminalize syringes as drug paraphernalia.
- Strengthen referral ties between CHOW and other HIV service providers.
- Explore if high risk syringe exchange clients need testing.
- All AIDS service agencies should provide access to clean needles.

11. Ensure That The Mental Health Needs of HIV-Positive People Are Appropriately Met.

- Mental health services should be available to all people living with HIV/AIDS who need them.
- Mental health services should be offered on a harm reduction model recognizing that people living with HIV and mental illnesses are likely to be using legal and illegal drugs.
- Mental health professionals providing these services should be trained in risk reduction counseling and understand the part they can play in reducing HIV transmission.
- Depression needs to be addressed systemically throughout the HIV-positive population through psychiatric and psychological interventions and through increased education to people living with HIV about the nature and risks of depression and need for treatment. All interventions should recognize the impact that depression has on risk behavior and non-adherence.
- Intensive therapeutic interventions are needed for a small number of people living with HIV related to complex issues such as sexual abuse, sexual compulsion, and domestic violence.

12. Ensure That On Going Support Around Disclosure Is Available To Sexually Active People Living With HIV.

- Support sexually active people living with HIV in figuring out when it is or isn't appropriate to disclose. Help them to develop strategies for disclosure when they feel that it is appropriate to disclose.
- Sexually active HIV-positive people should be supported in developing both verbal and non-verbal safer sex negotiation skills.
- Interventions should not be based on an assumption that people living with HIV will, or necessarily should, always disclose their HIV status.
- Interventions need to address the assumptions that both HIV-positive and HIV-negative people are making when engaging in sexual risk behaviors.
- Use social marketing campaigns like "Do ask. Do tell", "How Do You Know What You Know" and "HIV Stops with Me."

13. Explore and Implement Ways To Make Services More Accessible.

- Provide transportation to and from PHIP services.
- Make PHIP services mobile to go where people need it.
- Provide childcare for PHIP participants.
- In areas where there are high levels of HIV transmission and reluctance on the part of gatekeepers to provide access to prevention interventions (i.e., certain bars or sex clubs), DOH should team with community leaders to encourage development of mutually acceptable interventions.
- More effort needs to be placed on researching how we may most effectively engage HIV-positive SIW in PHIP interventions and what interventions, might be most effective. It is reasonable to expect that this effort may be slow in producing results, as time will probably be needed to develop trust relationships.
- Efforts should be made, particularly within the African-American, Filipino, and certain Pacific Islander communities to engage the church in constructive support of people living with HIV. Funding that has been expressly made available for this purpose should be sought.
- People living with HIV from communities of faith should be offered counseling that understands and gives credence to this particular worldview.
- The availability of outreach services should be enhanced and better publicized.
- Service delivery that allows individuals who have no interest in interacting with one another should be developed such as women specific services or gay men's programming separate from each other, even in different locations.
- No high risk HIV-positive Native Hawaiians and no women from the Neighbor Islands could be recruited for this project as well as no heterosexual men or IDUs statewide. Somehow bridges need to be built into these communities.
- A Person Living with HIV specific seat is needed on the CPG.
- CPG and existing prevention contracts along with Care Planning and existing case management contracts need to create collaborative task forces. Information sharing must occur including regular dialogues around values clarification. On-going cross training must be initiated.
- PHIP interventions for MSM should be implemented as soon as is feasible throughout the state. This population shows a readiness to accept these interventions and a desire to receive support in reducing risk behaviors.
- Interventions can begin by accessing existing clients of ASOs. Over time, service providers may be able to reach non-ASO affiliated clients through networking and trust building in communities impacted by HIV, and through HIV health care providers. Meanwhile, however, we have a pool of HIV-positive people at each ASO who are engaging in risk behaviors and are willing to accept support in making behavior change.
- Neighbor Island PHIP interventions for MSM should begin with individual level intervention placing greatest emphasis on ensuring anonymity/confidentiality of participants. These issues may best be addressed through outreach counseling allowing participants to choose the time and place. If the intervention provider can provide other non-HIV related services as well, this may provide a greater degree of confidentiality to clients. In this way, other community members may not assume that clients are meeting the provider for HIV-related counseling.
- O`ahu PHIP interventions can be offered on more levels and should overlap in services available to any given participant. The greater the variety of interventions that are available

to this population the better. Individual, group and community level interventions should be offered. Likewise, O`ahu interventions should initially address broader groups than just MSM. Specifically, women and some TGs have shown significant participation in GLIs and there is reason to believe they would be open to further interventions.

14. Current HIV Counseling/Testing Services Should Be Targeted To Most Effectively Reach The Highest Risk Sub-populations.

- Identify the sub-populations of high risk target groups most at risk for HIV.
- Design counseling/testing services to most effectively reach highest risk subpopulations.
- Use of outreach testing, rapid testing, and other innovations, as appropriate, should be implemented as soon as possible.
- Existing outreach counseling/testing services should be sustained, perhaps increased, and intensified to more directly focus on the most at-risk members of the population being targeted.
- Incentives to getting tested should be explored within these highest risk subpopulations, and appropriate incentives should be offered.
- Counseling and testing services for members of these groups should be well publicized within the subpopulation and available on demand.
- Turn around time for test results, particularly on Neighbor Islands must improve.
- More outreach counselor/testers need to be trained, especially targeting the most at risk and hard to reach groups.
- Anonymous and accessible testing needs to be expanded/made available in all prisons.
- More research should be done on what roles the US military and tourist populations play in our new HIV cases.

15. Provide Adequate Funding and Resources For PHIP Interventions.

- Make sure there is enough money for adequate staffing, enough money to provide competitive salaries and benefits, enough money for programmatic expenditures (participant incentives, etc.), and enough money to cover supervision, administration, evaluation, and overhead.
- Be sure that adequate resources are available for clinical supervision.
- DOH needs to define clearly to agencies that it subcontracts with exactly what PHIP is and how to do it. PHIP guidance from DOH/HRSA/CDC needs to be shared at all levels of planning and implementation.
- It is the opinion of the PHIP Project coordinators that for most prevention programs to be strong and successful a full time prevention department coordinator (or equivalent) is needed. Funding should be adequate enough that this program director does not have to do front line work and can focus completely on program development, implementation (including peer staffing/peer volunteers) and evaluation.

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Appendix A

DEMONSTRATION PROJECTS

1. Structural Interventions

A. Needle/syringe exchange – Hawai`i and a handful of other states have highly effective legal needle/syringe exchange programs.

B. Finding, reaching, testing unknown HIV-positive individuals for example:

- LA County uses case finding, based on targeted outreach in clinics and providers in Latino and African American communities. At-risk people identified are offered movie tickets for getting tested and having a risk assessment. When appropriate they are “invited into care or continued prevention care, depending on their needs.

C. Increase access, acceptability, and retention of infected individuals in HIV care settings.

D. Training HIV care providers to provide or link to effective prevention services. For example:

- The Indiana Integration of Care Project (IICP) was a partnership between the state Divisions of HIV/STD and Mental Health, and Indiana State University. It was designed to improve the capacity of Community Mental Health Centers (CMHCs) to manage an expanding HIV-infected population through provider training about HIV disease and about the HIV primary care system (including health care systems, ASOs, and AIDS political organizations. It included on-site CMHC service training and education, free telephone consultation, statewide HIV/AIDS update conference for mental health professionals, intensive training for certain CMHCs, and provision of mental health services for persons living with HIV. The program showed increased CMHC staff knowledge and attitudes about HIV and increases in the number of client referrals between and among CMHCs and HIV primary care sites.
- For the women in a methadone program, the state of Maryland coordinated HIV services between state mental health programs, HIV/AIDS programs, and substance use programs. Coordination efforts included training mental health practitioners regarding HIV; consortia participation by the Substance Abuse administration; annual mental health, substance abuse, and behavioral health conference; innovative HIV/mental health payment system; HIV counseling and testing in drug treatment centers; funding of two substance abuse case managers; and purchase of substance abuse treatment slots for persons with HIV. The “innovative” payment system stems from the fact that mental health services are “carved out” of the Medicaid system for reimbursement on a fee for service basis. “The challenge is to assure that the Ryan White health care system and participant providers are aware of the sources of payment through the mental health administration, and that these providers coordinate efficiently with these services. According to the state AIDS Administration staff, there is a somewhat greater level of coordination among HIV, mental health, and substance abuse services for people in Medicaid due to the mental health “carve out”, and the requirement that managed care organizations provide substance abuse services.

E. Develop and implement HIV prevention guidelines for care providers.

F. Use reimbursement/incentives to providers/patients for participating in PHIP.

G. Remove/prevent criminal sanctions related to one’s HIV status.

2. Individual Level Interventions

A. Prevention Case Management

- CDC guidance defines PCM as “client centered HIV prevention activities with the goal of promoting the adoption or maintenance of reduced HIV transmission behaviors.” Goals of PCM include providing specialized assistance to people with multiple and complex needs, offering individuals multiple session HIV risk reduction counseling, development of a client plan, coordination of services, follow-up monitoring and discharge. Practice of PCM was found to vary greatly at differing agencies implementing PCM programs. Many barriers to success were identified, including lack of interest by clients, lack of clear definition of PCM, lack of referral sources in the community, and difficulty with evaluating the outcome of case management.
- The San Francisco Department of Health document entitled “HIV Prevention Case Management, Standard and Guidelines for the Delivery of Services in San Francisco” is a useful example of how the San Francisco Community Planning Group took the CDCs 1997 guidelines and adapted them to their community.
- AIDS Project Los Angeles (APLA) offers PCM which they define as “a combination of individual HIV risk reduction interventions and traditional case management with the goal of promoting the adoption and maintenance of HIV risk-reduction behaviors by clients with multiple, complex problems and risk-reduction needs in order to prevent further spread of the virus, delay the onset of symptomatic HIV disease, and improve the client’s health status.

B. Psychotherapy or Intensive Counseling. Some examples of this include:

- AIDS Action Committee in Boston “offers intensive prevention counseling within the context of social services case management to individuals who have been assessed to be at very high risk for engaging in high risk behaviors.
- AIDS Project Los Angeles (APLA) offers individual level interventions including risk-reduction counseling, psycho-educational support, and a toll-free hotline in their Prevention Health Advocacy program.
- The California Partners Study was an intervention for heterosexual discordant couples that consisted of four sessions, followed up by two booster sessions. Each member of the couple was seen individually. The intervention was designed with the input of HIV-positive individuals and their negative partners. Researchers found that many of the couples were engaging in unprotected vaginal intercourse. The expressed need for “love and intimacy” plays an important role in sexual decision-making. “Some couples simply feel that they do not want to carry HIV into the bedroom.” For other couples, economics was a key issue. These couples had the perceptions that HIV infection actually connects people with important resources and they therefore did not see HIV infection as a completely negative consequence.
- William Fisher at the University of Ontario and Jeffrey Fisher at the University of Connecticut piloted a physician-directed HIV prevention intervention. A recent satellite broadcast featured this technique, which made adept use of Motivational Interviewing. Physicians used prescription pads to write “prescriptions for prevention”. The tape was ordered by AEP and should be available within the state. (The motivational interviewing skills and interviewing nature of this intervention could be adapted by anyone wishing to implement an individual level intervention.)
- HIV-positive women in three cities were exposed to a “high-intensity” 10-week cognitive behavioral relaxation training approach to stress management, incorporating

expressive/supportive therapy (CBSM-positive) or “low-intensity” psycho-educational individual intervention. Traditional condom and Reality condom use increased in both groups from 71% / 73% (respectively) to 100%.

- C. Active referrals/linkage to other needed services (e.g. drug treatment, mental health, medical, etc.)
- D. Knowledge delivery (e.g. transmission risk facts)
- E. Skills demonstration and practice (e.g. appropriate use of condoms, negation techniques, etc.). For example:
 - AIDAtlanta has a behavior modification program designed specifically for African American women.

3. Biomedical Interventions

- A. HAART: access, prescription, support for adherence (recognizing that we do not know how much this reduces transmission for an individual). Examples of this include Treatment Advocacy programs.
- B. Vaginal/anal microbicides – research studies and trials are underway.
- C. Vaccines – research studies and trials are underway.

4. Group Level Interventions (GLI)

- A. Closed and structured typed groups. Some examples include:
 - AIDAtlanta ran a program called HIV Stops With Me, a 6-week group for positive clients that emphasized the personal responsibility not to transmit HIV.
 - In 1999, the Asian & Pacific Islander (API) Wellness Center was to have piloted an 8-session GLI for gay Asian and Pacific Islander MSM. Disclosure was to be broken into two segments – telling your family and telling a date. Another component was to have dealt with safer sex, addressing assumptions about status, implications of new treatments and other issues. The group also talks about the meaning of being gay, API and HIV-positive. The group was to have been tested as a program over eight weeks or as a weekend retreat.
 - Teens Linked to Care (TLC) is a 3-module intervention for HIV-positive youth (14 – 23 years old), with each module consisting of several group sessions. Module 1 was 12 sessions focused on “staying healthy”. Issues addressed included adherence to medical treatment, disclosure of status, and stigma experienced by HIV-positive youth. Module 2 sought to help participants “act safe” and targeted risky sexual and substance abuse behavior. Topics included proper condom use and safer sex, and dealt with questions such as having children, disclosure and responsibilities to partners. Participants were encouraged to think about the emotional correlates to their substance use. Module 3 focused on quality of life issues and was designed to help participants feel good about and get pleasure out of their lives. There was a 40% reduction in the number of sexual partners and fewer HIV-negative partners. There was a 78% reduction in the number of unprotected sexual acts and a 30% reduction in the use of substances. Many participants reduced risky behavior spontaneously before the intervention began. Researchers noted the need to assess the appropriateness of the group intervention format, given that it may be difficult for some young people to be open and forthcoming in a group. Recruitment to the program was a challenge and took researchers longer than they had anticipated.

B. Support type groups. Examples include:

- Cynthia Gomez at UCSF put together SUMIT (Seropositive Urban Men's Intervention Trial) a 6-session intervention to bring together 50 HIV-positive men and create a social environment that does not feel like a traditional support group.
- Gina Wigwood at Emory University conducted a 4-session group level intervention called Women Involved in Life, learning from Other Women (WILLOW) for non-urban HIV-positive women. It focused on enhancing quality of life and reducing unsafe sex. One goal was to build the social networks of HIV-positive women, who did not have such networks in their rural areas. The four sessions focused on gender pride, emotion-focused coping skills, risk reduction, and healthy relationships. Although no outcome data was reported yet, 100% of participants were still involved at 6-month follow-up.

C. Drop-in or one-time type groups.

D. Retreats. One example of this is:

- AIDS Project Hartford implemented Project M a structured workshop for HIV-positive gay men. Curriculum was presented in 8 weekly sessions or a 2-½ day retreat. With a sound theoretical model at its foundation along with input from gay/bisexual men in its development. Project M has effectively empowered men to take charge of their sex lives. By focusing on a broad range of sexual health issues and by respecting HIV-positive gay/bisexual men to make informed choices about their sex lives, Project M has helped men to learn some of the skills that are necessary to have a satisfying and healthy sex life as an HIV-positive man". The intervention showed increased self reported likeliness to practice safer sex, increased ability to be creative in their sex lives, increased skills in talking to partners about safer sex, increased ability to handle sexual situations, increased motivation to practice safer sex, and increased experience of safer sex as erotic and enjoyable. Researchers conclude that "providing a safe environment where HIV-positive gay/bisexual men can come together to talk about sexual health and relationships in a sex-positive manner can be an effective risk-reeducation strategy.

E. Sero-discordant Couples. For example:

- Robert Remien at Columbia University provided an 8-session group level intervention for serodiscordant gay male couples. Previous research had identified "high levels of distress and hopelessness as well as feelings of isolation" among gay men in discordant relationships. The "most significant" finding was the expressed "desire for intimacy, desire to be close...the desire to be 'as close as I can with my partner.'" Remien has found the same concern when working with heterosexual couples. Researchers also noted "when partners in the study practiced risky behavior, it was often at the request of the negative partner." Remien reported that when it comes to issues around risk behavior, partners "are often experiencing the same fears and concerns, but they are not expressing them to each other because they feel a need to 'protect' each other emotionally. This avoidance of communication can contribute to taking risks." Retention of participants was a major challenge and several couples initially enrolled broke up. Remien believes this is because couples that are having relationship difficulty are attracted to this intervention. Other issues that HIV-positive participants expressed interest in, besides avoiding transmitting HIV to the negative partner, were self-protection, acquisition of STDs, reinfection, medical treatment issues, dealing with uncertainty and making future plans.

5. Community Level Interventions (CLI)

A. Media and social marketing – like:

- AIDS Action Committee in Boston has created a social marketing campaign targeting HIV-positive and HIV- gay men aimed at normalizing the discussion around avoiding transmission of HIV...during the ‘Don’t ask, don’t tell’ controversy, one poster read “Ask. Tell.’ Two others read, “Let’s stop new infections now. Don’t let yourself get infected. Don’t infect anyone else. You know what to do,’ and ‘No excuses, accidents, or rationalizations.”

B. Social outreach to overcome isolation and help increase access to HIV social/intimate partners if desired. Examples include:

- The Positive images program was set up by a 6-agency multicultural consortium of AIDS community organizations. The goals of the intervention include raising awareness about the role of HIV-positive men and women in HIV prevention, providing social networks that promote self-esteem and self-efficacy to practice safer sex, encouraging clients to reduce their risk for co-infection with other STDs and promoting HIV testing. The program has several components. A telephone chat line gives people living with HIV the opportunity to talk anonymously about their feelings concerning sex and safe drug use. Each chat lasts two and a half hours and is facilitated by one of the participating agency’s peer staff members. Several different chat groups have been set up including calls for women, gay Asian men, and Latinos. Facilitators can have private conversations with individual callers if there is a need to have confidential conversation. The Positive Images program also offers a drop in support group.

C. Popular opinion leader and leadership training – like:

- One innovative program at AIDAtlanta places trained volunteer educators in Internet chat rooms. The volunteers include hot button words in their profiles (such as bare -backing, drugs, etc.) to encourage other people online to contact them about prevention issues. Agency staff believe they have been able to reach many people who would not necessarily show up for an extended group session or other intensive prevention interventions.
- AIDS Project Los Angeles (APLA) provides Prevention Buddy Advocacy (PBA), an HIV-positive peer support program by which HIV-positive peer buddies provide social and psycho-educational support for behavior change to newly diagnosed individuals and provide them with medical and social service referrals.

D. Activism and Movement Building

Appendix B

Recruitment Flier

What you have to say matters!

We want to hear what you think. We are a group of HIV-POSITIVE people and friends who have been asked by the state to bring together HIV-POSITIVE people to create programs to help stop the spread of HIV. By supporting each other in making healthy choices, we have the power to stop HIV. We will be holding meetings in you area soon with qualified participants to hear what you have to say.

Your voice is an important part of this process.

- **Are you living with HIV/AIDS?**
- **Have you had unprotected sex (anal or vaginal), or shared needles, in the last year?**
- **Was at least one of the people you had sex with or shared needles with HIV-negative or you did not know his/her HIV status at the time?**

Small groups will be held in your area to help develop HIV prevention program ideas.

Participants will be selected to represent a broad variety of backgrounds and viewpoints.

**Everyone who comes to the meeting will receive \$50
and ono pupus
to say “mahalo” for your input.**

If you are interested in participating
Contact Jayne or Richard
(808) 521-2437

Appendix C
PHIP Screening Tool
ASO-affiliated

We know that living with HIV, it can be hard to always protect yourself and your partner. So, we want to help make programs where we can support each other in making healthy choices. To make sure we make the best programs possible, we want to get a group of people who represent the many different experiences of people living with HIV in Hawai'i.

In order to do that we need to ask you some questions. Some of these questions are very personal. You can choose not to answer a question, if you prefer. Anything you do tell us will be held strictly confidential. Is that okay?

If we have too many people interested, we will have to choose based on these answers to get a good mix of people. But we will let you know for sure, one way or the other whether or not you'll be invited to a focus group.

- 1. How long have you lived in Hawai'i? _____**
- 2. How old are you? _____**
Note: If younger than 18 - terminate call.
- 3. What do you consider your cultural/ethnic background?**
- 4. Do you consider yourself: Male Female Transgendered**
- 5. We will be having groups in your area soon. How can we contact you to let you know when they are happening?**

Name:

Address:

City/Zip:

Phone:

Is it okay to contact you at this number (discretion assured)?: Yes No

6. When would be the best time for you to come to a meeting?
 Day Evening Weekday Weekend Anytime
7. How long have you known your HIV status? _____
 Note: If HIV negative - terminate call.
8. Do you know how you got HIV? Yes No Unsure
 Explanation:
9. If yes, did you know they had HIV? Yes No
10. Did your partner know they had HIV at the time? Yes No Unsure
11. Do you consider yourself: Gay Bisexual Straight
12. Do you ever have sex with men? Yes No
13. Have you ever had unprotected anal or vaginal sex? Yes No
14. When was the last time you had unprotected sex? _____
15. In the past year have you had unprotected anal or vaginal sex with someone whose HIV status was negative or unknown? Yes No
16. If "Yes", how many times has this happened in the past year? #: _____
17. Have you ever shared needles? Yes No
18. When was the last time you shared needles? _____
 Note: If caller has not shared needles or had unprotected sex in past year – terminate call.
19. In the past year have you shared needles with someone whose HIV status was negative or unknown? Yes No
20. If "Yes", how many times has this happened in the past year? #: _____
21. Is there anything you want to tell us in regards to making programs that support people living with HIV to make healthy choices?
22. Those are all the questions I have. Do you have any questions for me?

Thank you so much for calling today. I want to assure you the information you gave me today will be kept strictly confidential. The information you gave me today will not be discussed in the focus group unless you bring it up yourself. I will be getting back to you soon with more information about the focus group.

Interviewer Notes:

Appendix D

PHIP Focus Group Facilitator Guide

Introductions

- **Welcome/Thank participants for coming**
- **Facilitators introduce themselves**
- **Participants introduce themselves**

Overview of PHIP

- **By and for HIV-POSITIVE**
- **Recognizes the difficulty of maintaining safer sex/needle use**
- **Purely voluntary – NO SEX POLICE**
- **Support each other in healthy choices**
- **Funded by CDC through the state – but separate from DOH**
- **Our focus: Community needs & input are MOST IMPORTANT**

Tape Recording

- **Only listened to by us, will not be shared**

Ground Rules

- **Confidentiality**
- **Be respectful**
- **Be non-judgmental**
- **No verbal or physical abuse**
- **Speak from your perspective**
- **Speak one at a time**

HIV Prevention vs. Education

- **Targeted vs. General**
- **Most at risk vs. others at lesser risk**
- **Behavioral change vs. education/awareness**
- **Skills building vs. knowledge**
- **Minimum 4 hours vs. often 1 hour**

Types of Interventions

Individual

- **Outreach**
- **Counseling (Therapeutic, peer)**
- **Clinical based (STD clinic, Dr. office)**
- **Partner Referral**
- **Counseling, Testing & Referral**
- **Prevention Case Management**

Group

- **Positively Sexy/Being Alive & Sexy**
- **Skills building workshops**

Community

- **Peer educator networks**

Focus Group Questions:

Given all that, what kind of prevention interventions do you think would work in Hawai'i for HIV-POSITIVE who have unsafe sex and/or share needles with people who are either HIV-negative or don't know their status?

Probe for:

- **Racial differences**
- **Gender differences**
- **IDU/non-IDU differences**
- **Rural/Urban differences**
- **Closeted/Out MSM differences**
- **Sexual orientation differences**

What kind of programs would you get involved with?

What would get you to become involved in a prevention program?

What do you think keeps people from coming to things like this?

What are ways around those barriers?

Get input on each individual type of intervention

Select 2 people from group to represent the group at the state level.

Thank participants and bring group to closure

Appendix E

Service Provider Discussion Guide

SYNOPSIS OF FINDINGS FOR PRIMARY PREVENTION NEEDS OF PEOPLE LIVING WITH HIV FOR KEY INFORMANT INTERVIEWS WITH SERVICE PROVIDERS

Richard Barton/Jayne Bopp
10/2001

Synopsis of Interviews with Non-ASO Affiliated HIV-POSITIVE Individuals (all from O`ahu)

The primary reasons given for not affiliated with an ASO were:

- Non-identification with or rejection of “HIV subculture”
- Limited need to approach an ASO
- Concerns for privacy
- Not aware of ASO services
- Embarrassment
- Rejection of services
- Negative experience with an ASO

Synopsis of Focus Groups/Interviews with High Risk HIV-POSITIVE Individuals.

O`ahu

- Participants were very open to having support around primary prevention issues
- Participants were not aware that support is available from prevention staff – they suggested making new clients familiarized with the prevention department upon becoming a client at the Life Foundation
- Participants were not excited about the idea of having case managers do primary prevention
- Participants strongly felt that working with peers – other HIV-POSITIVE people like themselves (or drug users like themselves, including age/ethnicity/gender, etc. would be most effective
- Trusting the prevention worker is extremely important
- All interventions must be non-judgmental
- Issues of confidentiality were very important – especially other HIV-POSITIVE folks not breaking their confidentiality
- Disclosure was a huge issue for participants and a large barrier to practicing safer sex.
- Participants felt that people in PSEs who did not bring up condom use/want to use condoms were either already infected or not concerned about being infected.
- Participants would like the issues of alcohol/drug use and depression addressed.
- Participants would like to find ways to meet other HIV-POSITIVE people – they would also like to learn relationship and communication skills
- Participants would like to have classes on what is safe and what is not

- Participants liked the idea of being hooked up with another HIV-POSITIVE “Buddy” who could provide them with all kinds of support, including primary prevention issues
- Participants wanted workshops on negotiating safer sex with long term partners who do not always want to use condoms
- Participants felt a more visible prevention campaign was needed in the bath houses and PSEs
- Positive response around group level interventions (GLIs) like Positively Sexy but voiced more of a desire for social events/groups
- Participants suggested that some of the barriers to coming to GLIs would be event time, location, transportation issues, person facilitating the group being judgmental/sex negative attitudes, fear of confidentiality being breached by other participants, if people are substance users being tired or leaving the house is an issue
- Phone lines, chat rooms and websites were listed as ways to access participants for GLIs
- Partner Counseling, Notification and Referral Services (PCNRS) – Accessing services through a doctor’s office not ASO/DOH. One participant was adamant that they would never disclose their partners to the health department if a work was going to be sent to that person’s home or work – all notification should be done by phone or mail.

Neighbor Islands

- The importance of confidentiality and anonymity could not be overstated due to the small/interconnected nature of their communities
- Trusting the prevention worker is extremely important – trust must be established over time
- The need for peer based interventions was repeatedly stressed – HIV-POSITIVE peers who were also similar in ethnicity, gender, age, etc.
- Prevention Case Management (PCM) must be peer based to effective too
- Participants felt that GLIs would not be realistic due to fears around confidentiality
- Participants felt that individual level interventions (ILIs) would be most effective
- GLIs maybe possible on a one time basis (not multiple groups) with lots of recruitment and incentives being used
- Social gathering GLIs would be the best way to access/recruit individuals for ILIs
- Participants felt that the threat of other STDs was not sufficient enough to get HIV-POSITIVE folks to practice safer sex
- For newly diagnosed individuals or people with confidentiality concerns, participants felt that mobile or outreach services, use of the Internet and a warm/hotline would be effective ways to reach them
- Participants felt that local people would not come to (ASO name deleted) because there were no openly HIV-positive staff working there.
- Participants felt that the Internet would be an effective outreach tool because its anonymous
- Participants believed that local people won’t even access HIV counseling/testing because their communities are so close they don’t even want to know if they HIV
- Participants reported that prevention programs start up but then die off - they reported the need for consistency with prevention programs
- PCNRS – Participants felt that people would “freak” if the “AIDS guy” or “Syphilis guy” showed up. One participant had a bad experience with PCNRS – When he had Syphilis the health department called his job, identified themselves as the health department and told his

employer they needed to talk to him right away. Even though his confidentiality was not broken it was an awful experience for him and he is against this concept.

- Participants felt that a clinic setting or private doctors office would be a good site for PCRNS
- Messages need to be clear about what is “safe sex” and alternative to unsafe sex should be offered
- Participants felt that it was too explicit to state that people are having unsafe and expect them to come to an intervention related to that – No one in a small community wants to admit to their unsafe behavior because of its implications (what they are doing and what other people in their community are doing)
- For literature and advertising – pictures of gay men may be stigmatizing – especially for NGI folks
- Distance and transportation is an issue for access
- There was a rumor reported about one ASO and a first hand report about another ASO that had staff who did not keep client confidentiality – this was seen as a huge barrier
- Participants felt that to alleviate confidentiality issues, prevention counseling could be effectively done by a private therapist, by a private physician or through other venues that are general health related.

QUESTIONS FOR SERVICE PROVIDERS

1. What if anything are you doing already in primary prevention with positives?
2. Given what you’ve heard from these findings, do you feel your agency could do this work now?
3. What barriers would there be to doing this work?
4. What additional resources would you need (training, \$, etc.)?

Appendix F

Day of Sharing Summaries

From *Day of Sharing* PHIP

Statewide Service Provider Recommendations

- HIV-positive people should be involved at all levels of the PHIP planning, developing and implementing process.
- The purpose of peer-based interventions is to provide services in an empathetic and non-judgmental manner.
- Delivering interventions that support skills building in the following areas: disclosure and its implications, safer sex issues, sero-discordancy in couples, relationship and communication issues, alcohol/drug use, depression and other related issues as identified.
- Delivery of services should be low threshold and flexible in order to offer clients a variety of ways to access services so they may do so in ways that are most appropriate, convenient and comfortable to them. (Thereby assuring client confidentiality, transportation issues and other barriers to access are addressed.)
- People need on-going assistance in a variety of ways of notifying or having partners notified of possible exposure(s). Refer to “Each One-Reach One” program.
- Provide technical assistance to help translate recommendations into practical application of delivery of services.
- Since some HIV-positive people are reluctant to go to ASOs or other HIV identifiable places, services must be provided in flexible, non-traditional manners. This may necessitate changes in the structures and philosophies within agencies. (TA may need to be delivered by an outside agency.)

Neighbor Island Consumer Recommendations

- Implement PHIP activities through Internet chat rooms and 1-800 talk lines.
- Question/answer section in local newspapers.
- HIV-positive people need to understand they need to continue to protect themselves – re: other STDs, other strains of HIV, increased information on risk factors, etc.
- Increase self-esteem (promote a positive life-style) within substance abuse programs, wellness workshops, etc.
- Provide for mental illness evaluation/treatment.

- Improve access through mobile outreach, locating ASOs in a multiplex, improve anonymity/confidentiality, address transportation issues, etc.

Neighbor Island Service Provider Recommendations

- ILI outreach interventions by non-case manager personnel.
- Education/prevention provided by HIV-positive staff when possible.
- Training/cross training for prevention and case management on issues such as being non-judgmental, confidentiality, behavior change skills, harm reduction, etc.
- Improve access to existing services or make services more accessible for substance use and mental health issues. These programs need to be more harm reduction centered.
- HIV Counseling/Testing: improve turn around time for results, provide more training opportunities for HIV-positive peer workers, increase the number of people providing services, and increase outreach testing.
- Increase resources (staff, funding, etc) for providing PHIP services.
- Programs need to be consistent and on going, RFPs should be for at least 3 years.
- All ASOs should provide clean needles.
- Social/community building gatherings important for accessing HIV-positive for ILIs and GLIs.

O`ahu Consumer Recommendations

- Increase peer based programs/staffing.
- Implement a confidentiality campaign – especially within the HIV-positive community.
- Increase cross training between prevention and care service providers.
- Integrate prevention and care.
- Increase accessibility/flexibility of programs (outreach, mobile services, phone line, internet, etc.).
- Have social and skills building GLIs.
- Implement a “Buddy System” – based on program Walt Senterfitt discussed.

- Expand/increase condom distribution.
- Ensure adequate funding to implement PHIP programs.
- HIV prevention should take the lead on PHIP programs.
- Non-judgmental and Harm Reduction approach must be required for all workers.

O`ahu Service Provider Recommendations

- Increase mobile services to rural areas for ILIs and GLIs.
- Hire and train local HIV-positive outreach person to provide PHIP activities.
- PHIP activities must occur in an environmental place conducive to confidentiality.
- Use phone lines to advertise PHIP services.
- Train service providers (re: mental health and substance abuse) around issues related to HIV and PHIP.
- Train *kupuna* and community leaders in confidentiality, HIV issues, providing linkages to HIV/PHIP services, etc.
- Funding needs to be provided for prevention education for case managers, PHIP prevention workers, support/housing providers, etc.
- Life Foundation prevention department should take the lead role in coordinating PHIP services on O`ahu.
- Agencies should collaborate to provide social opportunities for HIV-positive folks.
- Agencies should collaborate to provide substance use groups.
- Lead agency could subcontract with other agencies and provide them training.
- Increase outreach HIV counseling and testing.
- Increase GLIs for HIV-positive folks.
- Use student interns for prevention work.